DD INFORMATION EXCHANGE

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Editor: Kay Zwernik

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1989 AGENDA CELEBRATE ACCOMPLISHMENT

Circle of Friends

Note: The story below is a direct quote.

Twenty-five years ago, psychiatric nurse, Zigmus "Ziggy" Brazasukas, worked at the twelve-hundred bed Manitoba School for Retardates (now known as Manitoba Developmental Center), carrying out all the common-denominator duties one must do to manage fifty young boys on a single ward. But one boy, Clarence Asham, admitted in 1959 at age six, grabbed Ziggy's attention more each year. Although Clarence was blind and psychologists said he had an IQ of only 34, Ziggy noticed that the youngster liked to tap on things with a spoon--on the walls, the radiators, the table--anything that would make a noise--as if he were searching for a certain sound. And he would sit by the radio for hours, listening to music.

Ziggy had played the violin, mandolin, and accordion in Lithuania before World War II. He watched this tapping with increasing interest, and when Clarence was eleven, Ziggy tried some experiments. He played a note on a piano and watched Clarence tap the piano keys until he found the same note.

Then Ziggy began to take Clarence to his home after work.

"I got him acquainted with the accordion," Ziggy said. "He loved the sounds it made. So pretty soon, I was taking him home four or five nights a week. There was no program like this at the institution, so I had to do it during my 'off' hours....I had to do it as his friend."

For a month, Clarence was helped to make sense out of the accordion's buttons and keyboard. "It was hard work--really hard work," Ziggy said.

Then one day Clarence played his first tune, "Over the Waves."

"Once he had it, he had it good," Ziggy said. "After that, he loved playing so much--and so did I--that he came home with me on weekends, and we played together from 8:00 in the morning until 10:00 or 11:00 at night."

And so for many years, both did their time at the institution--one as an employee and the other as an inmate--while they looked forward to their time off together.

Ziggy also became Clarence's special protector at the institution. For example, some staff members saw Clarence as aggressive and suggested medication. "I fought it," Ziggy said. "After all, if someone took my radio, I'd punch the guy in the nose, too."

Through the years, Clarence's musical skill soared, surpassing that of his teacher. He could play a tune from start to finish after hearing it only once. He became proficient on the accordion and also learned to play the piano, guitar, and harmonica.

By the time Clarence was fifteen, he and Ziggy had become a well-known accordion duo...making 150 apearances across Canada. "After a five-day tour in Toronto (Clarence) came back speaking full sentences " said Ziggy. Clarence usually had responded by merely saying "yes" or "no." "After all, people listened to him and talked to him in Toronto. At the institution, people didn't really talk to him that much."

Today Clarence lives in Winnipeg. When you enter (his) home during the day, you walk into a house filled with music, one popular or classical piece after another. (Says a housemate,) Clarence can play anything He's so good at it, his friends try to stump him with obscure requests. As for his IQ...well, folks don't really know any more. But they are sure it isn't 34

More important, Clarence, now thirty-five, is beautifully connected to his community. He takes formal music lessons at the University of Manitoba, and he and (a housemate) are members of St. John's College Singers. With another housemate he attends every production of the Winnipeg Symphony Orchestra, the Winnipeg Opera Association, and the Manitoba Chamber Orchestra--then he goes home and plays every note he heard.

Although Ziggy is now retired, he is still Clarence's best friend, and visits him on a regular basis.

Note: This shortened story is taken from the book Circle of Friends written by Robert Perske and illustrated by his wife, Martha Perske. The book is filled with similar stories and experiences that will bring love and joy to any reader. Proceeds from the book are earmarked for several charities. The book may be ordered from: Abingdon Press, 201 Eighth Av. S., P.O. Box 801, Nashville, TN 37202. The cost is $9.95 plus $1.00 for postage and handling. This book is also available for loan from the DD Library at Metro Council. Call 291-6364 to reserve it.

FELLOWS PROGRAM BEGUN

On December 14 and 15, the Fellowship program for the FY89 DD Program's project in case management was formally initiated. On that date 16 individuals from throughout the state of Minnesota gathered for two days to learn how to help people with disabilities and their families go through the process of Personal Futures Planning. Beth Mount, one of the leaders in developing and promoting futures planning in the United States and Canada, provided the training meeting to the 16 Fellows. These individuals were selected by the Case Management Task Force from applications received by the DD Program.

Personal Futures Planning is a tool for fostering new ways of thinking about people with developmental disabilities. Futures planning helps groups of people focus on opportunities for people with disabilities to develop personal relationships, have positive roles in community life, increase their control of their own lives, and develop the skills and abilities to achieve these goals.

The Fellowship program has been designed to provide a cadre of trained people throughout Minnesota to help families and individuals with developmental disabilities begin using futures planning to help them in designing programs and services to meet their individual needs and desires. Families will be able to move away from a focus on the negatives and begin to focus on the capacities and gifts that all people bring to community, and opportunities and preferences of the person with a disability.

Announced in the October and November DD Information Exchange, the Fellowhip program will span the next ten months. During January and February the newly trained Fellows will work in pairs to assist two families each in completing a futures plan. The Fellows will meet again in April to discuss their experiences and further refine their skills and abilities in facilitating futures planning meetings.

Because the Fellows are a select group of individuals, they will have opportunities throughout the Fellowship program to interact with and receive training from several national leaders in areas related to futures planning. They will also learn how to train other individuals to lead futures planning meetings. This will enable further expansion of this process and empower greater numbers of families to use it to create positive futures for a person with a developmental disability.

The Fellowship program is part of the DD Program's third-year case management project and is made possible by a grant from the Governor's Planning Council on Developmental Disabilities.

The following individuals have been selected for participation in the Fellowship program:

Wendy Annis, Program Director
Cooperating Community Programs St. Paul

Terri Bauernfeind, Program Director
School for Social Development Minneapolis

Celeste den Daas, Advocate
ARC Suburban Burnsville

Theresa Halverson, Coordinator
REM Hennepin County SILS Minneapolis

Janice Jones, SILS Program Director
Clay County Developmental Services Moorhead

Jan Manchester, Mental Retardation Resource/
Placement/Intervention
St. Paul Public Schools St. Paul

Jennifer Mateer, Program Director
Cooperating Community Programs St. Paul

Marijo McBride, Advocate/Friend
West St. Paul

Daniel McCarthy, Director of Individual Advocacy
ARC Hennepin Minneapolis

Terry Morrison, Administrator
New Dawn, Inc. Worthington

Jennifer Otto, Student/Parent
Mendota Heights

Rhoda Robinson, Transition Specialist
Duluth Public Schools Duluth

David Ross, Program Specialist
Harry Meyering Center Mankato

Linda Rother, Student/Parent
Eagan

Mark Thiel, Social Worker II
Scott County Human Services Shakopee

Mary Kay Wasson, Asst. Program Director
Human Services Support Network St. Paul

FOR YOUR INFORMATION

Catholic Charities Initiates Award Program

This is the 10th anniversary of the U.S. Bishops' letter on people with disabilities. In this letter addressed to all Catholics, church communities are challenged to provide access and programs for people with disabilities. To mark this anniversary, Catholic Charities Program for Persons with Disabilities, Archdiocese of St. Paul and Minneapolis, is initiating an award. To be given annually, the award will provide recognition to a person or a program which has demonstrated success in enriching the dignity of persons with disabilities within the Catholic community. Preference will be given to programs or people involved in advocacy and social change. To receive further information and a nominating form, call Mary Jane Steinhagen at 612/291-4541 or write to: Catholic Charities, 328 W. Kellogg Blvd., St. Paul, MN 55102. Nominations must be postmarked by Feb. 28, 1989.

Course Offered In Job Coaching

During winter quarter Inver Hills Community College will offer a three-credit course entitled: "Job Coaching in Supported Employment." The offering is a skills development course for persons employed or seeking employment as job coaches for people with disabilities. It will cover the following topics:

- Overview and history of supported employment;
- Models of supported employment;
- Values and guiding principles;
- Job and task analysis;
- Case management;
- Training techniques;
- Career planning;
- Assessment and evaluation.

The course will be taught by Karl Samp, Placement Coordinator, Kaposia, Inc., at Neighborhood House, 179 E. Robie, St. Paul. It will begin on Jan. 9 from 6 to 9 p.m., and continue on Mondays until March 20. The fee is $87 for three credits. Add a 75 cent student fee and make check payable to Inver Hills Community College; mail to Registrar, Inver Hills Community College,8445 College Tr., Inver Grove Heights, MN 55075.

Educator Support Group

The Minnesota Technical Assistance Project (a cooperative project between the Institute on Community Integration and the Minnesota Department of Education) and the MNASH Integration Team are sponsoring monthly "Educators for Integration Support Group" meetings. These meetings provide an opportunity to brainstorm and problem-solve identified challenges, exchange ideas, support one another, and share successes and visions of learners with severe disabilities learning in typical school and community environments. Meetings will be held the second Monday of each month through May from 7 to 9 p.m. at AccessAbility, Inc., 360 Hoover St. NE, Minneapolis, MN. For more information, call Terri Vandercook at 612/624-4848.

Training And Technical Assistance Opportunities

Through the efforts of a recently formed Minnesota Alliance for Training and Technical Assistance, a new series of training and technical assistance seminars are being developed for early 1989. The Minnesota Alliance for Training and Technical Assistance is a group with representation from: Minnesota Association of Rehabilitation Facilities; Minnesota Developmental Achievement Center Association; Minnesota Division of Rehabilitation Services; Minnesota Habilitation Coalition; Minnesota Supported Employment Project; and, the Institute on Community Integration (formerly known as the University Affiliated Program at the University of Minnesota).

Each of the seminars listed below include the development of technical assistance plans which will assist participants in improving services in their home agencies after the seminar. In addition, some of these conferences will provide a "train-the-trainer" component following the particular event. Session titles include:

- **Department of Labor Standards, Payment Options, and Employer Incentives**, January 17 - 18, 1989, Earle Brown Center, St. Paul, Minnesota.

- **Business Orientation to Job Development**, March 16 - 17, 1989, Radisson Hotel Fargo, Fargo, North Dakota.

The following sessions will be occurring at Holiday Inn Downtown, Mankato, Minnesota:

- **Employment Specialist Training Course** (for job coaches), February 27 - March 2, 1989.

- **An Introduction to Supported Employment Concepts**, February 27, 1989.

- **Administrative Issues in Supported Employment (for administrative staff of agencies)**, March 3, 1989.

For further information regarding these sessions, please call the Institute on Community Integration at (612) 624-4848.

If you are currently organizing educational and training opportunities on issues related to developmental disabilities, please contact: Ralph McQuarter; Minnesota Department of Human Services; 444 Lafayette Road; St. Paul, MN 55155-3821. Tel. (612) 296-2160.

PUBLICATIONS

It's Never Too Early, It's Never Too Late

The Metropolitan Council's DD Program booklet on Personal Futures Planning will be ready for distribution on Jan. 11, 1989. Titled *It's Never Too Early, It's Never Too Late*, the booklet provides a rationale for futures planning for people with developmental disabilities and their families. It describes the steps involved in the futures planning process and the importance of a circle of support to assist the individual in actualizing the future that has been visioned for him/herself. Finally, the booklet explains how Personal Futures Planning can interrelate with the Individual Service Plan and the Individual Habilitation Plan as outlined in Rule 185. Numerous photos of children and adults in integrated settings are dispersed throughout the booklet.

Up to five copies will be sent free to residents of the Metro Area by calling the Metropolitan Council Data Center at 291-8140. Up to 10 copies may be picked up free by non profit organizations at the Data Center, Mears Park Centre, 230 E. Fifth St., St. Paul, MN. Copies for residents of Greater Minnesota and other areas of the country may be obtained by calling the Governor's Council on Developmental Disabilities at 612/296-4018. The publication of this booklet was made possible by a grant from the Minnesota Governor's Council on Developmental Disabilities.

Resource Guide

An *Integrated Education for Learners with Severe Disabilities: Print and Media Resources guide* has just been published. This guide provides descriptions of and source information for a variety of materials including journal articles; books and book chapters; manuals, reports and papers; newsletters and newsletter articles; audiotapes and videotapes. All the resources relate to the topic of integration in regular classes and other aspects of school life. If you are interested in obtaining a copy of this guide, send $3 to the Minnesota Integrated Education Technical Assistance Project, Institute on Community Integration, [illegible] Pillsbury Dr. SE, Mpls., MN 55455. Attention: Beth Nelson. Make checks payable to the University of Minnesota.

New Newsletter

Just published: a new issue of the *IMPACT* newsletter of the Institute on Community Integration (formerly the Minnesota University Affiliated Program on Developmental Disabilities). The purpose of this feature issue of IMPACT is to provide various perspectives on a number of integrated education topics, including successful integration practices and strategies, the changing roles of teachers, the appropriate role of research, the history and future of integrated education, and the realization of dreams of life in the mainstream for chidren with severe disabilities. To obtain a copy contact: Institute on Community Integration 612/624-4848. There is no charge for single copies, $1 per newsletter is requested for bulk orders.

WORKSHOPS/CONFERENCES

January 11, 1989

"Crisis in Residential Services" is the title of a workshop sponsored by ARC Hennepin County. The target audience is people with developmental disabilities, family members, professionals and advocates. Presenters will include Dave Kelly, Association of Residential Resources in Minnesota; Dick Lanigan, of Lanigan and Kolb, CPA; and Tom Miller of REM, Inc. The workshop will be from 10 a.m. until noon at the ARC of Hennepin County office, 2344 Nicollet Ave. S., #370, Minneapolis, MN. There is no fee for the workshop, but please call by Jan. 6 to register: 612/874-6650.

February 6, 1989

"Maximizing Staff Consistency in Program Implementation" is a one-day workshop on how to increase program effectiveness for individuals with special needs. Dr. Melissa Sweitzer, a licensed psychologist affiliated with the Institute for Applied Behavior Analysis in South Carolina, will conduct the workshop. Participants will learn to define expectations for staff, individualize and implement the Program Status Report (evaluation and feedback system for staff), design and implement a three-level system of staff training, and individualize and implement the Procedural Reliability System (system of checks and balances to ensure accurate program implementation).

The location is the Sheraton Airport Hotel, 2525 E. 78th St., Bloomington, MN. The registration fee is $85. Make checks payable to the Institute for Applied Behavior Analysis and send to the Institute, 417 Southampton Dr., Irmo, SC 29063. The workshop will run from 8:30 a.m. to 5 p.m.

INFORMATION
EXCHANGE

STATE
SUPPLEMENT
January 1989

Developmental Disabilities Program
300 Centennial Office Building
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
612/296-4018

**Member of
National Association of
Developmental Disabilities
Councils**

'SUPPORTED EDUCATION' COINED BY PARENTS: AN EXAMPLE OF SCHOOL INTEGRATION

"Soon after the passage of the Mandatory Special Education Act in Michigan and the concurrent passage of P.L. 94-142, the Education for All Handicapped Children Act, in 1975," said Dohn Hoyle, Executive Director of the Washtenaw Association for Retarded Citizens in Ann Arbor, "we began to urge consideration of, and then to demand that, classrooms be transferred out of our segregated facility into regular public schools." He continued, "We (through a committee) were successful in working with the intermediate school district with these efforts, such as the development of self-contained rooms for students labeled Trainable Mentally Impaired, which would be staffed by the school district. Another committee was formed to look at the situation for students with greater or multiple impairments, which urged attempting or piloting some level of integration short of the above."

Our association had also been concerned for some time about the so-called "day program" options for young adults. Even before the developments in the education arena, we had begun to push for community and supported employment for those with severe disabilities. Our efforts were inspired by such guest speakers as Lou Brown (University of Wisconsin in Madison) and Robert Perske, who discussed the report he did for the President's Committee on Mental Retardation in 1978--"The Leading Edge: Service Programs that Work." After hearing other leaders in the field, such as Jeff Strully, Kathy Bartholomew-Lorimer, Marion Jay, Beth Mount, and Jan Nisbet, we were struck with and began to wonder about the dicotomy of self-contained, segregated school rooms vis a vis integrated work and especially the individualized placement approach in supported employment."

"When I enunciated the logical extension of integration as it related to education," Hoyle continued, "the idea was totally dismissed at every turn." "Those few of us locally who continued to entertain the notion were branded as idealistic radicals," he added.

"Then I heard of Marsha Forest from Kitchner, Ontario Canada," he continued, "and had the opportunity to hear her speak in Madison, Wisconsin." "Not only was I blown away to hear that values could be pursued to their logical outcome, but also by the fact that it was being done on a large scale. Hoyle observed, "Personal relationships which we had been struggling with from our history in residential services had not only a place, but would be possible, encouraged, and facilitated. Just as we had come to see the efficacy and feasibility of supporting people in independent living and employment, we could do so in their educational career."

After initial discussions (with parents, other executive directors, and with board members), a plan to visit programs in Canada was devised, inviting parents and the intermediate school district superintendent. Tours were made in Kitchner, Toronto, and Hamilton, Ontario Canada. Considerable discussion took place on the trip back to Ann Arbor: 1) a parent revealed that she had never before thought that her daughter with severe and multiple impairments could ever have friends; 2) several commented on their desire to see that a commitment would come about that "each belongs"; 3) the superintendent described how impressed he was and how, if parental demand could be built, he felt he would have to respond; and 4) there was a consensus on what was right for all children.

Once home, the small group decided that others needed to hear and see what was possible. They decided to use the Millage Strategy--to use energy and resources to involve those who were in favor (of integration), rather than to attempt to seek out those who would need to change their minds or would take considerable convincing. Also, parents approaching parents would be the most effective method used. Each parent on the committee received a copy of a videotape of Marsha Forest and these tapes were shared with other parents who expressed an interest. These new parents were then invited to an ever expanding group of proponents of "supported education," a name that was suggested by one of the parents.

The initial meeting toward building parental demand started with a discussion of values and outcomes, followed by viewing the tape Regular Lives. The subsequent discussion was overwhelming. Everyone agreed to invite others and wanted to enlarge the group to include teachers, certain other professionals, and parents of children with and without an impairment.

"At this point," Hoyle continued, "certain things became clear: 1) many parents had previously thought about having their child with a disability participate in regular classrooms with their peers, but were either discouraged or afraid to say so to professionals (who must know better with all their training and experience) or, when they did express it were accused of trying to deny their child's impairment or its severity; 2) supported education seemed to most parents to be logical, natural, and so positive for the rest of their family, including extended family; 3) I was no longer leading a parade, I would have to run to keep up; 4) we could consciously expand to include others with no danger of damaging the 'movement'; and 5) brief mention of values and concentration on outcomes (including relationships) were powerful--how refreshing it was to ask parents to dream!"

"A delegation then met with the Superintendent of the schools. After assuring him that the demand would be there, he agreed to establish pilot programs during the 1989-90 school year," Hoyle exclaimed.

The Supported Education group continued to expand to over 100, including presidents of the Parent-Teacher Organizations and other parents whose children had no discernible impairment. Principals and local special education directors also attended. Hoyle added, "Teachers in self contained rooms in regular schools who had moved with trepidation from the segregated center, publicly announced that they would never go back and wanted this option to allow their students more opportunity."

There were a few who opposed the idea, such as a few parents, a special education teacher, and a small number of auxiliary personnel (who spoke the loudest and strongest). "However," Hoyle observed, "opposition was kindled by the belief that the strength of this effort and its widespread support would leave the number who chose the segregated option so small it wouldn't be accommodated in the future, which was pretty telling!"

Hoyle then concluded, "The culmination of our efforts came about with: 1) a spectacularly attended presentation by Marsha Forest and Brian Cullen (the elementary principal in Kitchner), who were enthusiastically welcomed by parents that evening; and 2) a daytime presentation to professionals (by invitation only). Later, the larger committee met to select delegates to serve on the implementation team."

Hoyle added, "Local circumstances may dictate other methods, but this is what seemed to work in Ann Arbor. I can only attest to the success here, and the effort is worth it and correct!"

For further information, contact: Dohn Hoyle, Executive Director; Washtenaw Association for Retarded Citizens; 1945 Pauline Blvd.; Ann Arbor, Michigan 48103. Tel. (313) 662-1256.

UNIVERSAL DESIGN FROM DREAM TO REALITY

According to Elizabeth Schmidt Ringwald, special projects manager of Home magazine, "Universal design represents a new approach for home builders and remodelers while challenging inventors, architects, and interior designers to rethink the old rules. It calls for creativity and a sensitivity to individual needs in the search for better answers to ever-present problems." Her article, "On the Eve of Universal Design: Homes and Products that Meet Everyone's Special Needs," appeared in the October 1988 issue of Home: Creative Ideas for Home Design.

She stressed, "Home is where we have the most control over our physical environment, but most of us still put up with a lot of inconvenience. As children, we did not fit in a world designed for adults. As aging adults, we do not fit in a world designed for younger people. If we happen to face additional physical challenges, we are disabled by a world designed only for the fittest. Fortunately, inventive products and home plans are beginning to bridge the gap."

"From adjustable-height sinks to faucets that sense your hands underneath and flow at a preset temperature, innovative design is slowly creeping into the marketplace," Ringwald observed. "Universal design comes in many forms: homes that are meant to empower individuals, not set up barriers; appliances and tools that amplify abilities rather than handicapping them. Universal design strives to make every place and product work better for everybody. It brings great ideas home."

The article is replete with examples and attractive photographs of how universal design can improve the quality of life for everyone, such as: building homes flexible enough to accommodate peoples' changing needs; movable furniture with reversible fabrics; counters with adjustable heights; all-directional, adjustable shower heads for a wide range of users; infrared sensors, voice-recognition programs and talking appliances; telephones that understand your voice, write notes to you, talk to your friends and go almost anywhere. The lists of creative ideas are expanding at an astonishing rate. A very informative "Buying Guide" was added to Ringwald's article.

With kind permission of the author and publisher, this article has been reproduced and is available by contacting: Minnesota Governor's Planning Council on Developmental Disabilities; 300 Centennial Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

WELFARE FRAUD HOTLINE ESTABLISHED

Minnesotans who suspect welfare fraud may now call a special statewide, 24-hour-a-day hotline to have their complaints investigated by the Minnesota Department of Human Services. The toll-free hotline number for Greater Minnesota is: 1 (800) 627-9977. People calling from the Twin Cities metropolitan area should dial: (612) 297-4147.

Callers may leave a message of any length on an answering machine. Callers may remain anonymous or may leave their name and phone number if they want a staff person to contact them. All calls to the hotline will be evaluated and, if warranted, investigated. Programs that are subject to fraud and may be reported to the hotline include: Food Stamps, Aid to Families with Dependent Children, General Assistance, Work Readiness, Emergency Assistance, Minnesota Supplemental Aid, and Medical Assistance.

Examples of potential fraud activities include:

- not reporting all income, resources and assets;
- having an absent parent return to and live in the home;
- receiving assistance for a child not at home;
- forging assistance checks;
- not reporting a marriage;
- receiving assistance in two or more counties at one time;
- misrepresenting household size; or
- selling food stamps for cash.

Suspected fraud activity may also be reported in writing to: Welfare Fraud Hotline, Minnesota Department of Human Services; Human Services Building; 444 Lafayette Road; St. Paul, MN 55155-3834.

PUBLICATIONS

--Circles of Friends: People with Disabilities and Their Friends Enrich the Lives of One Another, written by Robert Perske, illustrated by Martha Perske, Abingdon Press, 1988. Author Robert Perske, writes, "We long for wisdom to make the world more decent and tolerant and caring, a world where all of us figure in one another's survival. We believe that much of the wisdom needed for this task comes from reaching toward those we may have been programmed to avoid." This book emphasizes the value of pure and simple friendships. True stories show how these circles cut across age groups, generations, and races, and how the hearts and worldviews of everyone can be enriched. Available from: Abingdon Press; 201 Eighth Avenue, South; P.O. Box 801; Nashville, TN 37202. Tel. 1 (800) 251-3320, toll free. In addition, order forms are available from: Minnesota Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

--The 1988/1989 Catalogue of the G. Allan Roeher Institute in Canada is available. Publications, films, and videotapes are listed covering a variety of topics, such as: advocacy, aging, behavior issues, community living, education, employment, history, and leisure/recreation. The G. Allan Roeher Institute is Canada's national institute for the study of public policy affecting persons with an intellectual impairment. The institute has two goals: 1) to identify and anticipate future trends that will support the presence, participation, self-determination and contribution of persons with an intellectual impairment in their communities; and 2) to foster the exchange of ideas leading to new ways of thinking about persons with an intellectual impairment. The Institute is sponsored by the Canadian Association for Community Living, a voluntary organization bringing together over 400 local and 12 provincial and territorial associations. Contact: G. Allan Roeher Institute; 4700 Keele Street; Kinsmen Building; York University; Downsview, Ontario; CANADA; M3J 1P3.

--**Community Transition Interagency Committees: Yearly Summary, 1988**, Interagency Office on Transition Services, Minnesota Department of Education. This is a report to the Minnesota Legislature, which passed a statute in 1986 requiring local school districts to establish community interagency transition committees. The purposes of these local committees are to coordinate services and plan for the transition of youth with disabilities from special education to post-secondary education, training, employment, and community living. The report describes the new legislation, presents an overview of administrative and related legislative initiatives to improve transition services, discusses the progress and status of community transition interagency clommittees, and presents recommendations, and discusses future directions for community transition interagency committees as they continue to evolve in Minnesota. Copies of the report may be obtained from: Interagency Office on Transition Services; Minnesota Department of Education; 800 Capitol Square Building; 550 Cedar Street; St. Paul, MN 55101. Tel. (612) 296-4163.

RESOURCES

Nonaversive Behavioral Management Hotline. A new hotline for referral and assistance has been established at the National Research and Training Center on Community- Referenced Behavior Management at the University of Oregon. The purposes of the service are to: 1) refer individuals needing technical assistance with a severe behavior management problem to an identified consultant in the caller's region; 2) answer requests for information; and
3) refer requests for in-service to the training branch of the project. Special services are available by calling:
1 (800) 451-4060.

The National Rehabilitation Information Center (NARIC) offers help to people with special needs, providing assistance in serching for devices that can make the difference between dependent and independent living. Funded by the National Institute on Disability and Rehabilitation Research, part of the U.S. Department of Education, NARIC has access to a vast library and to computer data bases listing thousands of aids and devices for anyone with a disability. Professionals are available by telephone for consultations from 8:00 a.m. to 8:00 p.m. Eastern time, Monday through Friday. There is a charge of $10.00 for the first 100 bibliographic or product ditations and $5.00 for each additional 100 citations. For more information, contact: NARIC; 8455 Colesville Road; Silver Spring, MD 20910-3319. Tel. 1 (800) 34-NARIC, toll free.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.**

LENDING LIBRARY SELECTIONS

Partnership for Quality Services: Keeping the Quality of Life Growing, Volunteer Monitor's Handbook and videotape, Association for Retarded Citizens of Minnesota, 1988. Partnership for Quality Services is a volunteer monitoring project designed to ensure and promote quality services for persons with developmental disabilities. This project, funded in part by the Minnesota Governor's Planning Council on Developmental Disabilities, demonstrated how consumers of services, members of the community, and professionals can work together to develop quality programs and assure that people with disabilities can lead valued lives in the community. Volunteer monitors address quality of life issues, such as community participation and personal relationships. The monitor's handbook, used in training of volunteers, provides basic values based in principles of normalization, the monitor's responsibilities, and policies and procedures for implementing change. The videotape has two segments: 1) an overview of the project; and 2) simulations of monitoring visits to community programs, depicting each quality of life indicator in detail.

VIDEOTAPES AVAILABLE ON LOAN (VHS 1/2 inch):

Don't Be Surprised! (20 minutes) National Association for Down Syndrome. A panel of experts, adults who have Down Syndrome, tell about their life experiences--their likes and dislikes, their successes and failures, and best of all, their positive outlook via a sense of humor. These individuals, who were once described at birth as "hopeless candidates for institutionalization," are shown as they are today--working at real jobs, living independently, and fully participating in and contributing toward life in their communities.

Regular Lives (28 minutes & 33 seconds) State of the Art Productions for Syracuse University, 1988. Children with developmental disabilities participate in typical school settings, an affirmation that integrated classrooms can work. This production is intended to educate the general public, parents, and teachers about the values and advantages of including children rather than excluding and segregating them because of their disabilties.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

If you no longer wish to receive this newsletter,
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Mears Park Centre, 230 East Fifth Street.,
St. Paul, MN 55101

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The following is contained in Minnesota statutes regarding education for children in this state. It is in Chapter 120. DEFINITIONS; GENERAL PROVISIONS.

> 120.011 Purpose statement
>
> In accordance with the responsibility vested in the legislature in the Minnesota Constitution, article XIII, section 1, the legislature declares that the purpose of public education in Minnesota is to help all individuals acquire knowledge, skills, and positive attitudes toward self and others that will enable them to solve problems, think creatively, continue learning, and develop maximum potential for leading productive, fulfilling lives in a complex and changing society.

Jeff's Aerobics

The fourth grade student walked into his classroom, sauntered over to the corner and asked, "Are you getting ready to do Jeff's aerobics?" Julie, one of Jeff's teachers, was laying out all of the bolsters and other equipment around the mat on the floor. She was preparing to give Jeff his daily routine of physical therapy and positioning exercises. To an adult this routine looks probably just like physical therapy, but through a child's eye, it was merely 'aerobics.'

Jeff attends an elementary school in Duluth, Minnesota and is in the fourth grade full time. It is not his neighborhood because that school is not physically accessible. However, it is a regular elementary school. Jeff has cerebral palsey, uses a wheel chair, is probably profoundly retarded. He wears diapers, is non-verbal, takes medications for seizures and has had what his mother refers to as "spells" since birth. Jeff needs accessibility.

Jeff, who turned 11 in January, participates with his classmates in all the classroom activities from gym to reading circle. In this program, Jeff is acquiring knowledge, skills and positive attitudes toward himself and others that will enable him to solve problems, think creatively, continue learning, and develop maximum potential for leading a productive fulfilling life in a complex and changing society.

Jeff was born with severe anoxia and had respiratory and kidney failure. He needed a respirator for one week and was in the Neonatal Intensive Care Unit for two and one-half weeks. After he came home he slept only two hours a day. His mother, Lynn Frigard, noticed that he was more rigid than a normal baby. There was seizure activity. At three months, Lynn knew there was something wrong. At six months, Jeff was diagnosed with cerebral palsey. Even at an early age, Jeff began having spells in which he would cry, go into extension, hold his breath and turn black and blue. These spells sometimes lasted 20-to-30 minutes. At times, as an infant, they occurred as often as 40- to-50 times a day.

The spells and the mere two hours of sleep a day resulted in mounting stress and anxiety in the family. Mom thought she was going "crazy." At 10 months of age, Jeff went to a medical foster home, and at 18 months, to a group home in Duluth. The decision that this was absolutely necessary was made long before Jeff ever left home. Keeping the rest of the family together made necessary this decision. The family has always been very involved in Jeff's activities; members of the family see him at least weekly.

There were many preparations made before Jeff became a full time student in the fourth grade. Previously, Lynn had thought, "It's okay for kids who can talk," when referring to integrated education. She credits Partners in Policy Making for changing her mind. Partners is a 12-month program sponsored by the Governor's Planning Council on Developmental Disabilities. It exposes parents and advocates to best practices and trends in the field of developmental disabilities.

Last year Lynn asked the Duluth schools to include Jeff in a regular class two hours-per-day. The time gradually increased during the year. This year Lynn asked for full-time placement.

To help make this a successful experience, Lynn and the special education and regular education teachers interviewed together for Jeff's aide. They chose someone with no special education experience and no preconceived notions. The teacher who volunteered to include Jeff in his class referred to Jeff as the "new student" rather than the "handicapped student."

Jeff's equipment takes up a large space in the classroom. As a result the students share space with Jeff. The equipment in a corner includes a mat, side lyer, wheel chair and prone stander. All of the students have tried the wheel chair and prone stander.

Jeff has been easy to integrate, according to his mother, since he has no maladaptive behaviors. His spells have gradually decreased over the years. They have completely stopped in the classroom. The students have been involved in making decisions about Jeff. They have been asked, "How can Jeff be a part of this classroom?" The students devised a number of ways to deal with his drooling. One suggested bandanas instead of bibs. Another brought some home-made cover-ups with sleeves and decorated them with markers. Still another made a T-shirt with slits up the side to be easily removable when it gets wet.

Jeff loves school. For the first time in his life, it makes a difference to him when he is sick and doesn't go to school. Now he interacts with children; before he only interacted with adults.

He was Pee Wee Herman at Halloween. He went to the school open house, and he was also a part of his class' role in the Christmas program. The kids push him around the roller rink. In the lunch room, they fight over who is going to eat with him that day. A fourth grade student from another class was overheard asking one of Jeff's classmates in the hallway, "How come you guys are so lucky to get Jeff and we don't?"

Jeff has a lot of gifts and capacities that he brings to community:

- — gorgeous brown eyes with long eyelashes
- — good auditory perception
- — loves classical music
- — a greatsnuggler loves to go horseback riding
- — swims at the pool
- — likes changes in temperature and being in the sun
- — responds to people when they talk to him
- — likes activity--doesn't like to be still
- — likes walks
- — likes to go to malls
- — likes to be a part of things

These are the gifts Jeff brings to his fellow students in the fourth grade in Duluth. You see, Jeff is acquiring the knowledge, skills, and positive attitudes toward himself and others that will enable him to solve problems, think creatively, continue learning, and develop maximum potential for leading a productive, fulfilling life in a complex and changing society.

> ***"If a child can't learn the way he is taught, we must teach him the way he can learn." (Author unknown)***

RESOURCES

Mothers' Respite Retreat Weekends

The Association for Retarded Citizens of Hennepin County is sponsoring a series of retreat weekends for mothers of individuals with developmental disabilities. The weekends are led by experienced staff and offer a chance for group and individual activities. All retreats begin Friday evening and end at noon on Sunday. The cost for the weekends is $50. The retreats are held at the Eden Wood Camping and Retreat Center in Eden Prairie.

Dates for coming retreats include February 10-12 for moms of infants and preschoolers; March 17-19 for moms of school-age children; April 28-30 for moms of infants and preschoolers; and May 5-7 for moms of teens and young adults. For more information and a registration form contact the ARC of Hennepin County at 612/874-6650.

Understanding Individuals with Autism

A professional, video-based instructional package, "Understanding Individuals with Autism," is now available for staff training. Providing quality programs and services for individuals with autism and related disorders of severe behavior problems and communication deficits is a problem often faced by educators and residential, vocational and recreational service providers. The straight forward approach of the materials is designed to provide a concise overview of the Autistic syndrome, and to develop or expand staff skills including: behavioral observation and record keeping; planning for success; strategies for developing a communication system; principles of program planning in community settings. This instructional program was developed by Outcomes, Inc. and the Twin Cities Society for Children and Adults with Autism (TCSAC) through a grant from the Minnesota State Planning Agency.

The instructional package includes:

Two, 20-minute video training tapes of real-life situations;
1. Introduction to Autism: Overview
2. Introduction to Autism: Communication
Comprehensive training materials, supporting activities and resources; and Facilitator's instructional videotape and manual. To order or request more information contact: Outcomes Inc./TCSAC. 253 East Fourth St., St. Paul, MN 55101. 612/228-9074.

NEW APPOINTEES TO DDAC

The Metropolitan Council announces new appointees to the Developmental Disabilities Advisory Committee. New members will serve three-year terms although some are fulfilling unexpired terms. The DDAC welcomes the following new members:

Robin Dols, Lakeville Parent,
District 14

Barbara Kempf, Minneapolis
Provider, District 5

Avis Kruger, Golden Valley
Consumer, District 11

Leslee E. Lane, Brooklyn Center
Consumer, District 10

Troy Mangan, St. Louis Park
Provider, District 11

Carol C. Mark, Woodbury
Provider, District 16

Timothy J. Moriarty, Coon Rapids
Parent, District 8

Paula L. Reeves, Lakeville
Parent, District 14

Cindy S. Scattergood, Richfield
Parent, District 12

James S. Temple, Minneapolis
Provider, District 6

A POEM

"Let Me Be" by Richard Barbour, 1984, Copyright

I'll just do the best I can,
and won't apologize to anyone;

I'll just go outside and spread my wings,
Take pleasure in the simple things;

Fly a kite, a lakeside walk,
With one who cares, a gentle talk;

And pass the days and try to be,
The I, unique; the special, me;

And try to live a life of note,
Just like other, ordinary folk,

For I am just the same as you,
Feel pride in fantastic things I do;

Like you, at times, feel hate and pain,
And fight to find peace again;

Like you feel joy and laugh and shout,
And cherish what it's all about;

The words may not come so well,
But I can love and I can tell;

And I can feel and I can know,
The direction that the winds may blow;

Just let me be, watch me fly,
Just let me be, just let me try;

And I'll just do the best I can,
And then I'll be a freer man . . .

Freer to learn, freer to give,
Freer to find myself and live.

CONFERENCES/WORKSHOPS

February 25, 1989

The ARC St. Paul is sponsoring a workshop on Case Management Services. The workshop will be held at the Holiday Inn Capitol (I-94 and Marion St.) from 9 a.m. to 4 p.m. Its is for parents, self-advocates, family members and professionals who want more information about the purpose of case managment and the ISP and its benefits. Specific sessions will include the Department of Human Services Rule 185, defining goals, determining needs, overview of case management, designing objectives and ways to meet services. Pre-registration by Feb. 10 is required. The fees are $25 ARC member, $35 non-member and $45 professional. Send registration to: ARC St. Paul, 65 East Kellogg Blvd., St.

Paul, MN 55101. Scholarships are available by calling Jackie Stalley at 612/224-3301.

February 24-26, 1989

The 9th Symposium on Management of Persons with Multiple Handicaps is a multidisciplinary conference for service providers helping people of all ages with profound retardation and multiple handicaps. Presenters are from the local area as well as other states. Participants may attend from one to six sessions at various rates. Some of the topics include:

- —A Model for Consultation Services
- —Playing with Children with Multihandicaps and Their Families
- —Developing Functional, Reciprocal Communication for Individuals Who Lack Symbolic Skills
- —Ball Techniques for Treatment of Persons with Multihandicaps
- —Developing Skills for Working with Families of People with Handicaps
- —Mainstreaming Preschoolers with Handicaps
- —Self Esteem Issues: Strategies for Self Care and Program Development
- —Drugs Prescribed to Children with Special Needs
- —Sensory Problems: Sensitivity and Self Stimulation

The symposium will be held at McGuires Inn, 1201 W. County Rd. E, St. Paul. College credits are available. For further information on complete listings, fees and a registration form contact: Eileen Richter, OTR, 12015 N. July Ave., Hugo, MN 55038.

March 14-17, 1989

"Children '89: The First 100 Days: A Children's Initiative for President Bush and the 101st Congress" is the theme of the Child Welfare League of America 1989 National Conference, which will be held at the Washington Hilton in Washington, D.C. For more information and registration, contact: Child Welfare League of America; 440 First Street, NW, Suite 310; Washington, DC 20001-2085. Tel. (202) 638-2952.

March 15-17, 1989

The 5th National Traumatic Brain Injury Symposium, will be held at the Maryland Institute for Emergency Medical Services Systems, Baltimore, Maryland. This three-day national conference will feature more than 150 researchers and clinicians from more than 25 states and Cananda, who will share the latest advances in brain injury rehabilitation, including recent updates in pediatric brain injury rehabilititation. For registration and other information, contact: Roberta Schwartz; 5th National Traumatic Brain Injury Sysmposium; Speech-Communication Disorders Program; Maryland Institute for Emergency Medical Services Systems; University of Maryland at Baltimore; 22 South Greene Street; Baltimore, MD 21201-1595.

March 18-21, 1989

The American Society of Aging Annual Meeting will be held in Washington, D.C., at the Grand Hyatt Hotel. The theme will be "We the People: Forming a More Perfect Union." For more information and registration, contact: American Society on Aging, 833 Market St., Suite 512, San Francisco, CA 94103. Tel. 415/543-2617.

April 5-8, 1989

The 1989 International Fragile X Conference will be held at the Clarion Hotel at Stapleton International Airport in Denver, Colorado. Based upon responses from the 1987 conference participants, this meeting will be of benefit and value to anyone who lives with or works with individuals having Fragile X Syndrome. Fragile X Syndrome is an inherited abnormality of the X chromosome which frequently causes learning disabilities or mental retardation. For more information and registration, contact: The National Fragile X Foundation; Conference Manager; Expectations Unlimited, Inc.; P.O. Box 655; Niwot, Colorado 80544.

June 19-30, 1989

"Introduction to Augmentative and Alternative Communication" is a two-week institute sponsored by the University of Nebraska-Lincoln. It's for educators, speech-language pathologists, occupational and physical therapists and others in need of an introductory course in augmentative communication. The first week will cover characteristics of persons who are nonspeaking/writing, display and symbol techniques, assessment, intervention planning and guided laboratory experiences. During the second week students will participate in interaction and facilitator instruction and learn about strategies for instruction, service delivery models and funding and legislation. For complete information on fees, travel arrangements and accommodations contact: Nancy Brown, University of Nebraska-Lincoln, 202 Barkley Memorial Center, Lincoln, NE 68583. Tel. 402/472-3955.

July 6-8, 1989

A Celebration of Family: The First National Conference on Family Support for Families with Children with Disabilities will be held at the Hyatt Regency Cambridge Hotel, Cambridge (Boston), Massachusetts. This conference will be sponsored by Human Services Research Institute, United Cerebral Palsy Associations, Inc., and the U.S. Department of Education, National Institute on Disability and Rehabilitation Research. For more information and registration, contact: United Cerebral Palsy Association, Inc.; Community Services Division; 1522 "K" Street, NW (Suite 1112); Washington, DC 20005. Tel. (202) 842-1266.

INFORMATION EXCHANGE

STATE SUPPLEMENT
February 1989

Developmental Disabilities Program
300 Centennial Office Building
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
612/296-4018

Member of
National Association of
Developmental Disabilities
Councils

STUDY INDICATES P.L. 94-142 A SUCCESS

A five-year Collaborative Study of Children with Special Needs, conducted by the Robert Wood Johnson Foundation, concluded that the procedural guarantees of the Education for All Handicapped Children Act (P.L. 94-142) are now securely in place, and have been translated into services for children with varying degrees of success. The success is largely attributed to the fact that "Our schools initially decided to grant special education relatively high status within their administration and because schools recognized that as many as 10 percent of chilren nationwide have special education needs," the authors stated. The report is entitled, Serving Handicapped Children: A Special Report, 1988.

Initiated in 1975, federal law established the principle that children with handicaps and nondisabled children are equally entitled to a free, appropriate education provided by their local public school systems. The law stated that, to the fullest extent possible, children with disabilities should be educated in the "least restrictive environment." The purpose of the study was to find out what difference this landmark legislation had made in the lives of children with handicaps, their families, their teachers, and their non-handicapped schoolmates.

According to the Annual Reports to Congress that have been submitted by the Office of Special Education and Rehabilitative Services of the U.S. Department of Education, the national proportion of special education students grew from eight to 11 percent of the school population after the implementation of P.L. 94-142. Most of this growth was concentrated in two previously underserved groups. First, was the relatively small number of children with severe handicaps, who formerly had been institutionalized or kept at home with few or no educational opportunities. Second, was the very large group of children with learning disabilites. The number of children in this group grew from 800,000 (22 percent of students with special needs) in 1976-77 to 1.9 million (43 percent) nine years later.

This Collaborative Study was conducted in five large metropolitan school districts: the Milwaukee (WI) Public Schools, the Houston (TX) Independent School District, the Charlotte-Mecklenburg (NC) Schools, the Santa Clara County (CA) Office of Education, the Rochester (NY) City School District. A carefully selected sample of more than 2,000 children with handicaps representing the special education population was studied. The writers of the report cautioned the readers, "While some of these findings undoubtedly correspond to the national experience, they are specific to the five sites studied and connot be generalized to the country as a whole."

Some of the major findings were as follows:

- The special education population is extremely diverse. It includes not only large numbers of children who are categorized as having learning disabilities and speech impairments, but also children with emotional disturbance, mental retardation, blindness, deafness, physical handicaps, chronic illness, or multiple handicaps.
- Although a vast majority of special education students are attending regular schools and spending at least part of the day in a regular class, over 30 percent of the children studied spent their entire school day in special classes (28.4 percent) or in special schools (3.9 percent). Children classified as having mental retardation (comprising 11.6 percent of the total sample) were proportionately in more segregated settings--82.8 percent of those with mental retardation attended separate schools (33.2 percent), or special classes (49.6 percent). Only 17.2 percent of those with mental retardation were integrated into regular classes (1.3 percent), attended regular and some special classes (6.4 percent), or special and some regular classes (9.5 percent).
- Parents were generally satisfied with the services their children with disabilities received, which is a marked contrast to parental views prior to the implementation of P.L. 94-142. Where dissatisfaction was expressed, many parents of children with learning disabilities were not happy with their children's academic progress, and many parents with children with mobility impairments with no intellectual impairments were not satisfied with their children's social integration. Children with emotional/behavior problems were reported by their teachers to have less improvement than any other group, which suggested to the researchers that a substantial investment of attention is needed by these children.
- Among the children with special needs, only 29 percent were diagnosed before age five. Schools are the major site of identification for most children

with special needs. Nonetheless, physicians identified between 15 to 25 percent of the children with learning disabilities, speech impairments, emotional disorders, and hyperactivity.

— While P.L. 94-142 intended that the development of child's Individualized Education Program (IEP) involve parents, usually less than half actually attended their child's IEP meeting. According to several school principals, parents who failed to attend IEP meetings cited many reasons: work schedules, personal problems, lack of child care, no transportation.

— On the average, special education costs nearly twice as much per child as regular education.

Although the study substantiated enormous gains, it also documented several key areas for continued concern and attention: 1) serious gaps still exist, such as some children find themselves in a 'gray area' with respect to defining their problems and meeting their needs. For example, children with mild mental retardation, children whose emotional problems interfere with learning, and young adults rarely have access to services that will help them make the transition to adult life; 2) families reported encountering stress related to their child's handicap in the areas of work, housing, vacations, and friendships-- documenting the tremendous needs families have for respite care, day care, and summer camps; 3) the availability and use of services should not obscure concerns about the quality of services; 4) training of teachers and other personnel--teachers need to have available more resources such as paraprofessionals, volunteers, itinerant teachers and to use parent support groups as a positive resource; and 5) parents may need more help in becoming involved in the education of their children with handicaps.

The writers of the report concluded, "We have relied heavily on our public school systems as agents for social change, nonetheless, maintaining and expanding the capacity of the public education system to serve handicapped children will depend on parents' continued vigilence and on the hard work of education and health professionals who design and implement programs addressing the day-to-day needs of individual children. Ongoing monitoring is essential to assure that the gains that have been made are not lost and that the remaining chanllenges--along with the inevitable new ones--are met."

Copies of this and other related reports may be obtained by contacting: The Robert Wood Johnson Foundation; P.O Box 2316; Princeton, NJ 08543-2316.

GOVERNOR APPOINTS NEW MEMBERS TO GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

Governor Rudy Perpich has appointed several new members to serve for a term of three years on the Planning Council on Developmental Disabilities:

— Sharron Hardy, St. Louis Park, replaces Bob DeBoer;

— Michal Jorgens, Crookston, replaces Sharon Shapiro;

— Maribeth Ahrens, Virginia, replaces Richard Amado;

— Antoinette Lippert, St. Paul, replaces Marcel Bourgealt;

— Linda Horkheimer, Cottage Grove replaces Helmi Lammi;

— Linda Rother, Eagan, replaces Barbara Pihlgren;

— Thomas Schwartz, Eden Prairie, replaces Margaret Lindstrom.

— Edward Skarnulis, from the Minnesota Department of Human Services, was reappointed to the Council for another three-year term.

The Governor's Planning Council on Developmental Disabilities is charged with supervising the design of a three-year state plan on the quality, extent, and scope of needed services for people with developmental disabilities; to monitor and evaluate the implementation of the state plan; and to review state services plans for people with developmental disabilities.

MINNESOTA SELECTED AS TRAINING SITE ON NONAVERSIVE BEHAVIORAL PRACTICES

Minnesota was recently selected to participate in a national training project under the direction of Robert Horner, Ph.D., from the University of Oregon. The Minnesota Department of Human Services will coordinate the training of trainers in practical nonaversive approaches for persons with developmental disabilities who have severe behavior problems.

The University of Oregon was awarded a five-year contract by the Office of Special Education and Rehabilitative Services, U.S. Department of Education, to establish and operate a research and training center on community-referenced technology for managing severe behavior problems of persons with severe disabilities. In addition, the University of Oregon will collaborate with five universities across the country in a comprehensive effort combining research, training, and technical assistance activities geared to produce an effective technology that can be administered by local school and community personnel. The five collaborating universities are: San Francisco State University, the University of California at Santa Barbara, California State University at Hayward, State University of New York at Stony Brook, and Marshall University in Huntington, West Virginia.

Staff from these universities will provide onsite training to individuals selected to participate in four initial demonstration projects in Minnesota. Individuals who receive this training will then train others in the state. This "train the trainers model" will then be replicated throughout the state.

For more information, contact: Gerald Nord; Division for Persons with Developmental Disabilities; Minnesota Department of Human Services; 444 Lafayette Road; St. Paul, MN 55155. Tel. (612) 297-3828.

MINNESOTA WILL RECEIVE TECHNICAL ASSISTANCE ON COMMUNITY INTEGRATION

Minnesota has been selected to receive one year of technical assistance from the Research and Training Center on Community Integration, Center on Human Policy, Syracuse University. Syracuse will be working with the Division for Persons with Developmental Disabilities, Minnesota Department of Human Services, and the Eleven County Special Needs Project. The Eleven County Special Needs Project is a coordinated effort between the Department of Human Services and eleven counties to cooperatively develop resources to support individuals who have been identified as having special needs by the Welsch Negotiated Settlement as they move to their home communities from regional treatment centers. The counties participating are: Anoka, Blue Earth, Brown, Carver, Faribault, Hennepin, Martin, Ramsey, Scott, Washington, and Watonwan. There will be statewide dissemination of information generated from the project as issues are identified, strategies developed, and supports are provided to foster community integration of persons with developmental disabilities. For more information, contact: Alex Henry; Division for Persons with Developmental Disabilities; Minnesota Department of Human Services; 444 Lafayette Road; St. Paul, MN 55155. Tel. (612) 296-0939.

REQUEST FOR PROPOSALS RELEASED BY PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

The Governor's Planning Council on Developmental Disabilities recently published a Request for Proposals (RFP) that would address the following priority of the Council: "Increased accountability to individuals with developmental disabilities of all ages to increase independence, productivity, and integration into the community." Applications are due in the Council office no later than 4:30 p.m. on **April 21, 1989.**

Eligible organizations may apply for grants for the purpose of implementing the Council's priority (to promote increased accountability) in the following areas:

1. Improved individual planning--to improve accountability by increasing the quality of individual planning throughout Minnesota for individuals of all ages and types of disabilities; to enable persons with disabilities to participate more effectively during individual planning sessions; and to provide persons involved in individual planning, such as case managers, with material that will help them to evaluate the process and outcomes of individual planning.

2. Advocacy training and support--to increase the empowerment of individuals with disabilities and create self-advocacy organizations to assist individuals who are unserved and underserved.

3. Building communities--to support the process of building communities for persons with developmental disabilities. In order for individuals with disabilities to become full participants in the community, it is necessary to acquaint policy makers, public officials, and generic organizations with the factors that are preventing full participation and to enlist them in the efforts to achieve full participation.

For a copy of the RFP and application forms, contact: Ron Kaliszewski; Governor's Planning Council on Developmental Disabilities; 300 Centennial Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018 (voice), or (612) 296-9962 (TDD).

PUBLICATION

Connections: The Newsletter of the National Center for Youth with Disabilities. The first edition of this quarterly newsletter was recently released. This publication will serve as a vehicle for sharing information and points of view among people concerned with adolescents with chronic illness or disability and their transition to adult life. The National Center for Youth with Disabilities, a collaborative project of the Society for Adolescent Medicine and the University of Minnesota's Adolescent Health Program, is supported by a grant from the Bureau of Maternal and Child Health. A major activity of the center has been the creation of a National Resource Library of information about youth with disabilities. For more information, contact: National Center for Youth with Disabilities; Adolescent Health Program; University of Minnesota; Box 721-UMHC; Harvard Street at East River Road; Minneapolis, MN 55455. Tel. 1 (800) 333-NCYD, or (612) 626-2825.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement *section of this newsletter.* Tel. (612) 296-4018.**

LENDING LIBRARY SELECTIONS

<u>Videotape Series: Selections from an Oral History of Policy and Advocacy in Developmental Disabilities as Reflected in the Lives and Works of Elizabeth M. Boggs, Gunnar Dybwad, and Rosemary F. Dybwad.</u> This ten-volume series was developed by the University Affiliated Program, University of Medicine and Dentistry of New Jersey; and the Robert Wood Johnson Medical School, with funding from the Administration on Developmental Disabilities, Office of Human Development Services. The videotapes include:

Elizabeth M. Boggs, Ph.D.:

--The Evolution of Public Policy Towards People with Developmental Disabilities: A Half Century Perspective;

--The Evolution of the Developmental Disabilities Legislation, Parts I, II, & III (3 tapes, respectively); and

--The Social Security Act and Mental Retardation, Parts I, II, & III (3 tapes, respectively);

Rosemary F. Dybwad, Ph.D.:

--Normalization and Self-Advocacy; and

--The Parent-to-Parent Movement and the Development of the International League of Societies for Persons with Mental Handicaps;

Gunnar Dywad, Ph.D.:

--The Role of the Courts in the Renewal of the Field of Mental Retardation; and

--The Pioneering Role of the National Association for Retarded Citizens.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

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(TIME-DATED MATERIAL)

D D INFORMATION EXCHANGE

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1989 AGENDA CELEBRATE ACCOMPLISHMENT

Editor's note: Several months ago this column had a story about "Kyle's Day at the Pool" written by his mother, Linda Horkheimer. The story related an incident that changed Linda's view of her son's participation in the community. She saw for the first time the real value of Kyle having regular friends and participating in typical activities. Naturally, the story was written from Linda's point of view. The story below is also written by Kyle's mother, but reflects how she thinks Kyle sees himself and his world.

A DIFFERENT VIEW OF MYSELF

I'm five years old, and I have to say I find life pretty amusing. I think watching people putting food into their mouths is so funny. Watching them chew is hilarious, and the looks on their faces after they've swallowed cracks me up. I love how the adams apple moves around, and every time it goes up and then down I laugh so hard I almost tip over. Breaks me up I have to be real careful when I'm observing these things though. It never fails. Some spoilsport always tries to trick me by putting some food into my mouth. But I'm too smart for them. I just leave the room. If I am too slow, and somebody sneaks some food in, I really try to be a good sport about it, and I usually at least try to chew it. It's so difficult that I shudder and gag until I can't stand it anymore. The only thing left to do is spit it out. But, I've got my timing down pretty well, and I can tell by the looks on their faces whether they're going to try something or not. Then I make tracks.

Another one of my greatest pleasures is splashing in the toilet. That is so much fun It's an activity I highly recommend. My Mom doesn't allow toilet splashing, but I've learned that one should always at least check the bathroom door, because lots of times they forget to lock it. Also, when Mom shoos me away from the toilet, that gives me time to turn on the faucets. When she shoos me away from there, I head straight for the bathtub, but that's always the last resort. Those old shower curtains almost always get in the way, and when I try to get around them, they usually fall down. Once the metal rod fell right on my head I cried and my Mom hugged me, and I hugged her back.

I love to hug my Mom. Sometimes I get too excited and I accidently scratch her or poke her eye or squeeze her adams apple (I think that is the funniest thing) or pull her hair. When I do those things, she gets real sad, and that makes me feel bad. My Mom sings to me a lot and I just love that. We practice "eye contact" and I hate that game. She won't give me what I want unless I make "eye contact" with her and sometimes I forget. But I know she means well.

She's gone a lot to "conferences, workshops and meetings," whatever those are. And she spends a lot of time talking on the telephone about me. She makes me laugh because she always makes at least two calls in a row. The first time, she gets all red in the face and her arms and hands fly in all directions and she paces back and forth and she talks really fast. Then she gets off the phone and she cries and tells me how much she loves me. I always hug her back, because she thanks me and says she needed that. Then she makes her second call to one of her friends and she gets all excited again.

I don't understand why she's so emotional. I'm very happy and I have a lot of fun most of the time. Sometimes I feel sad when nobody wants to play with me or when I knock down the blocks and the other kindergartners tell me, "No, stop that " I don't mean to offend anyone. but when kids get mad, I feel terrible. I love to be around kids. They talk to me and I feel real relaxed around them. The adults want me to do things that I either don't like to do or things that are hard, or just plain silly. I do my best to please everyone, but some days I feel grumpy and not very cooperative. Sometimes I don't feel like participating, (I hear Mom say that word a lot) and I tune everyone out. She always gets a concerned look on her face when I do that. She insists on holding me, and she talks to me a lot and sings to me, and then I feel better. She always believes in me. She says, "Kyle, you are capable." I'm not sure what that means, but it makes me feel good when she says it. She gets real emotional, and she cries a lot, but to be fair, she laughs a lot too. And wow, can she ever talk Even though I can't talk at all, my Dad says she talks enough for both of us.

Sometimes I overhear her on the telephone, and she says that I have epilepsy, cerebral palsy, autistic tendencies and that I've been labelled severely mentally retarded. I'm not sure what all those things mean. She never tells me. She just tells me that I'm capable and that she loves me.

Well, you'll have to excuse me now. Mom's down in the laundry room and someone left the bathroom door wide open

A Call for No More Teachers of Students with Severe Handicaps

Citing the changes in the last decade in advocacy for educational approaches, Susan and William Stainback write that personnel preparation programs in colleges and universities need to change their approach in training future teachers. In a recent TASH Newletter article they say that ten years ago they advocated for a cadre of specialists specifically trained to work with students with severe disabilities. This resulted in special labels, special rooms, and special teachers. Separation from typical kids in regular classrooms with regular teachers was the norm. The Stainbacks make several recommendations to teacher preparation programs to promote the integration and acceptance of all students into regular education:

— Work with regular educators to integrate best practices/techniques from special education into regular education courses and field work;

— Become professors in regular education;

— Identify instructional areas (community referenced instruction, behavior management, or support facilitation) rather than a category of student (severe handicaps);

— Offer specialization in regular education teacher preparation such as support facilitation, community referenced curriculum, alternative communication systems or supported and competitive employment. In implementing this recommendation, teachers would be employed as regular education personnel. They would provide consultation to regular education teachers and/or instruction in the above mentioned areas to any student with or without disabilities who needed it.

The Stainbacks call for the colleges and universities to set an example for integrated education. The current system of categorization allows special education teachers to legally only work with students with disabilities and regular education students to work with so-called nonhandicapped students. An effort is needed at all levels from the state departments of education to educational institutions to work together to overcome the barriers in order to facilitate the integration of all students into regular classrooms. (TASH Newsletter, Feb. 1989)

FOR YOUR INFORMATION

Open House Planned for Library and Computer Center

The Courage Center in Golden Valley invites families of children with disabilities and professionals in the disability field to an open house for its Lekotek and COMPUPLAY centers on Friday, March 10 from 11 a.m. to 7 p.m. at 3915 Golden Valley Rd., Golden Valley. It will feature hands-on demonstrations of specially adapted toys, adapted computers and special computer software for children with disabilities.

Lekotek is a play resource center and toy lending library intending to integrate children with disabilities into their families and their families into the community. It is the 50th Lekotek site in the nation. COMPUPLAY is a unique computer center through which families can borrow, on a short-term basis, computer software and toys, many with special adaptations.

Human Services Referral and Placement Service Available

The Social Service Network is a personnel consulting firm that provides temporary social service staff in human service programs such as group homes, DACs and supported employment programs. Staff are screened to meet the qualifications, standards and requirements of the requesting agency. Examples of types of staff positions available include job coach, residential assistant, therapist, community trainer, and more. This service can assist agencies experiencing difficulty filling positions or during periods of turnover. For further information, contact Eric Nikolai, Social Service Network, 2402 University Ave. W., Suite 204, St. Paul, MN 55114. (612) 645-8540.

Appointees are Sought for Both Federal and State Positions

At the federal level, President Bush has appointed a Transition Committee for the Appointment of Persons with Disabilities. Its purpose is to involve persons with disabilities in his administration. The President asked the committee to "beat the bushes" to find qualified people with disabilities and qualified parents of children with disabilities to apply for jobs concerned with disabilities as well as other jobs throughout his administration.

Persons interested in both paid and non-paid appointed positions can ask for a list of critical positions yet to be filled and send resumes to: Chase Untermeyer, Director of Personnel, Transition Team, 1825 Connecticut Ave. NW, Room 912C, Washington, DC 20007, or Evan J. Kemp, Jr., Commissioner, Equal Employment Opportunity Commission, 2401 E. St. NW, Room 512, Washington, DC 20007.

At the state level, there is an opening on the Governor's Interagency Coordinating Council on Early Childhood Intervention (ICC) for a parent of a child under age seven with a handicapping condition. Committee members receive a $35 per diem, expenses and reimbursement for child care. Applications are available from the Secretary of State's Office, 180 State Office Bldg., 100 Constitution Ave., St. Paul, MN 55155. (612) 296-2805.

Mental Retardation Sabbath-Sunday

The weekend of March 11-12 has been designated Mental Retardation Awareness Weekend to focus attention on the needs and abilities of people with mental retardation. Church and synagogue members are encouraged by the ARCs to invite their organization to participate in this weekend and to become involved with people with mental retardation. For further information or to get copies of brochures for distribution, contact one of the local ARCs: St. Paul 224-3301, Hennepin 874-6650 or Suburban 431-3700.

Office of Ombudsman for Mental Health and Mental Retardation Fully Operational

The Office of Ombudsman for Mental Health and Mental Retardation investigates complaints from any source concerning the actions of an agency, facility, or program that provides services or treatment to persons with mental illness, mental retardation or a related condition, chemical dependency, or emotional disturbance. The complaints may deal with inidividual client concerns or concerns of a more general or systemic nature.

Created by the Minnesota Legislature in 1987, the Office is an independent agency, not a part of either the Department of Human Services or the Department of Health. The Office now has a staff of 16 persons, 11 of which were transferred from DHS.

In investigating complaints, the Office of Ombudsman can:

- — mediate or advocate on behalf of clients;
- — center and view premises of an agency, facility or program;
- — examine records of an agency, facility or program;
- — gather information about and analyze the actions of an agency, facility or program;
- — investigate the quality of services provided to clients;
- — review the circumstances surrounding deaths and serious injuries of clients in residential and acute care facilities.

The Ombudsman, after an impartial and objective review of a complaint, may recommend that an agency, facility or program 1) modify or cancel its actions; 2) alter a rule, order or internal policy; or, 3) take other action to ensure that the corrections are made. After making recommendations, the Ombudsman may continue to monitor the situation to insure that corrective action has been taken. The Ombudsman may send recommendations directly to the Governor and can make public its recommendations and conclusions.

For more information about the Office of Ombudsman for Mental Health and Mental Retardation, call 296-3848 in the Metro Area or 1-800-652-9747 (toll free).

PUBLICATIONS

Assessment of Individuals with Severe Handicaps by Diane M. Browder, Ph.D

This book is a resource for professionals who are involved in developing educational programs for individuals with severe handicaps that focus on their life skill needs and that utilize applied behavior analysis. Assessment requires synthesis of many areas of knowledge and experience. The book assumes that the user would have knowledge of existing resources for educating individuals with severe handicaps and some background in applied behavior analysis.

Two principles guide the book--normalization and applied behavior analysis. The book provides detailed procedures for selecting and conducting socially valid assessments in both the home and the community. There are five case studies throughout the book--two children, one adolescent, and two adults--to enable the reader to see each part of the approach used in the book in operation.

Areas of assessment include the home, community, related skills (communication, motor skills and academics) and social skills and interfering behavior. The book covers task analysis as a system for ongoing assessment and as a means to create skill chains that promote generalization and provide opportunities for assessment as well as instruction.

The book is available from Paul H. Brookes Pub. Co., P.O. Box 10624, Baltimore, MD 21285. The cost is $23.95 and the stock number is #729.

Your Child's and Adolescent's Mental Health: A Resource Guide for Parents

The Mental Health Association in Hennepin County has produced a guide for parents to provide them with a source of readily available information for making use of mental health services. The guide describes some of the challenges a parent may face when seeking mental health services for their child. Topics addressed include: when to seek help; crisis services and planned services; finding a therapist; follow-up care and case management. A list of resource organizations is also provided.

To receive a copy of the guide send $1.00 per copy (up to 5) to Mental Health Association of Minnesota, 328 East Hennepin Ave. Minneapolis, Mn. 55414.

WORKSHOPS/CONFERENCES

March 7, 1989
PACER Center is sponsoring a free workshop for parents of children with special needs. The two topics will be planning educational services for children with special health needs and health care financing. A representative of the Department of Human Services will explaining the various programs available to families. The workshop will be held at the Jewish Community Center, 1375 St. Paul Ave., St. Paul from 7:00 to 9:00 p.m. To register, call PACER at 827- 2966.

March 9, 1989
A second workshop sponsored by PACER covers what parents should know to develop an appropriate education for their child with special needs. Covered topics include:

- —assessment--what should be learned from tests and from personal knowledge of the child
- —due process rights--parental rights and children's rights
- —advocacy--parents advocating for their child
- —team staffing--facilitation parent-professional communication at conferences

The workshop will be held at the Holiday Inn St. Paul Capitol, I-94 and Marion St. in St. Paul. It will run from 7:00 to 10:00 p.m. Call PACER at 827-2966 to register.

March 18 and April 1, 1989
"The Five P's of Meetings" is a leadership training program for parents who serve on a local or state committee or who wants to learn better skills about participating at meetings and may have a desire to chair a committee in the future. The two day workshop is sponsored by ARCs Suburban and Minnesota, Early Childhood Regional Coordination Project and PACER. It will be held at the Catholic Aid Association Building basement, 3499 Lexington Ave. N., Shoreview. The time on both days is 9:00 a.m. to 2:30 p.m. There is no charge and a box lunch is provided. The following topics will be covered:

March 18
    Positive Individual Styles
    Parliamentary Procedures
April 1
    Policies and Politics
    Parent/Professional Roles/Interagency
    Positive Resolution of Issues

For reservations, call PACER Center at 827-2966.

March 10,1989
"Simple Technology for Learners with Severe Disabilities" is a one-day workshop which will provide an overview of automated learning devices featuring a display of over 60 commercial components including switches, control units, special adapters and reinforcers through hands on experience. The use of these technologies in functional settings will be emphasized. The workshop will be held at McGuires Inn and Conference Center, 1201 W. Cty. Rd. E, Shoreview. The workshop will run from 9:00 a.m. to 4:00 p.m. The fee is $60. For more information, contact ABLENET at (612) 331-5958 about the ALD Workshop.

March 14, 1989
The Vinland National Center is sponsoring a workshop on "Assessment and Programming for Students Who Have Visual and/or Hearing Impairments." Topics covered are assessment of infants and young children, functional vision assessment, entry/exit criteria, orientation and mobility and socialization of students with sensory impairments. The program will run from 9:00 a.m. to 2:30 p.m. at the Vinland National Center, 3675 Ihduhapi Rd., Loretto. There is no charge for the workshop. For more information and directions, contact Marie at (612) 479-3555. Lunch will be provided, but preregistration is necessary.

April 6-8, 1989
The Minnesota Speech-Language and Hearing Association will hold its annual Spring Convention at the Minneapolis Marriott City Center in downtown Minneapolis this year. Topics covered will include:

- —Assessment and treatment strategies for children and infants with disordered swallowing and feeding
- —Classroom language intervention
- —Central auditory processing
- —Electronic augmentative communication aids
- —Real ear measurement techniques
- —Vestibular evaluation
- —Digital hearing aid technology
- —Counseling clients and families
- —Psychosocial aspects of communication problems
- —And more

For further information and registration materials contact: Martha Cooper, 2509 Thomas Av. S., Minneapolis, MN 55405. W: (612) 374-5591 or H: (612) 627- 2356.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
March 1989

Developmental Disabilities Program
300 Centennial Office Building
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
612/296-4018

Member of
National Association of
Developmental Disabilities
Councils

STUDY OF NURSING HOME RESIDENTS DOCUMENTS IMPORTANCE OF INDIVIDUAL CHOICE AND AUTONOMY

An article that appeared in The New York Times, entitled, "Life's Basic Problems Are Still Top Concern in the Nursing Homes" (January 19, 1989), summarized the results of a recent national study conducted by Rosalie A. Kane, a social worker at the University of Minnesota. The article, written by staff writer Gina Kolata, observed that this study is one of the first efforts to ask people residing in nursing homes about their concerns of daily life.

Describing the findings of the study as "a gold mine of information," Dr Kane said that the overwhelming problems that nursing home residents face are centered on the difficulty of maintaining their personal autonomy in an institutional setting.

RESIDENTS' RANKING*	QUESTION	AIDES' RANKING
1	**Going out.** Leaving the home to shop, walk, etc.	3
2	**Phones and mail.** Contacts with family and friends.	10
3	**Roommates.** Having a choice of roommate.	5
4	**Care.** Routines requiring aid, such as bathing.	7
5	**Activities.** Recreation, entertainment and crafts.	1
6 (tie)	**Food.** Type of food, mealtimes and being fed.	4
6 (tie)	**Money.** Access to and control of funds.	9
7	**Getting up.** When and if to get up in the morning.	6
8	**Going to bed.** When to go to bed at night.	8
10	**Visitors.** Which guests come and when they come.	2

As part of the survey, the researchers found that what residents viewed as important often differed from what the nursing home aides thought the residents would consider important. Residents, for example, when asked to rank items on a list in order of importance, rated being able to leave the home for a short period of time, to go for a walk, or to run errands as most important. Second in importance, they cited being able to use a telephone.

Aides, by comparison, thought that residents would be most concerned with choosing their activities at the home, a choice that the residents rated 5th of 10. The aides placed leaving the home third on their list, and using the phone 10th.

One hundred fifty residents and the same number of nursing aides at 45 nursing homes in five states were asked how important they considered it for patients to have a choice in various aspects of nursing-home life:

* Items were ranked by percentage of residents who said they considered them very important; aides' perceptions sometimes varied considerably.

Residents responding in the survey had asked why they could not choose their roommates and why they had to have roommates at all. They also asked why they were sometimes kept tied down to a bed. They questioned why they had to adhere to a rigid schedule dictating when they awoke, ate, and slept.

Arthur Caplan, director of the Center for Bioethics at the University of Minnesota, said that, for him ". . . a whole new world unfolded. There were ethical problems that I had never given any thought to." Dr. Caplan saw the message of the study this way: "The medical community has a challenge in front of it. We have been thinking of nursing homes in medical terms, not in terms of a residence, and we have to convince ourselves to think otherwise."

Margaret P. Battin, an ethicist at the University of Utah, noted that "Ethics has, by and large, concentrated on high-tech issues." Dr. Battin said that because the issues Dr. Caplan calls "the ethics of everyday life" are not flashy or glamorous, they tended to be overlooked.

The study results were presented at a conference but have not yet been published, according to the Times article.

"PARENTS' BILL OF LEGITIMATE EXPECTATIONS" DEVELOPED BY THE ARC/MARYLAND

The following document was prepared by the Association for Retarded Citizens/Maryland Oversight and Monitoring Committee and was approved by their Board of Directors on December 11, 1988:

Parents'* Bill of Legitimate Expectations

Preamble

Involvement of parents and other family members in life planning for an individual within the family unit who has a disability is founded in tradition and practice. The principles recognizing the value of parental involvement exist in current laws and regulations governing the operation of programs and is essential to the success and effectiveness of the volunteer oversight and monitoring concepts promoted by the Association for Retarded Citizens of Maryland. The ARC/Maryland believes that the type of participation by parents enumerated in this document should be encouraged and nurtured by organizations providing services for persons with developmental disabilities.

The ARC/Maryland recognizes that the participation of an advocate in the affairs of any individual with a disability is contingent upon that persons' approval. The sanctity of individual rights must be maintained in the use of this Bill of Legitimate Expectations.

- Parents have a legitimate right to expect to be a part of their son's or daughter's life.
- Parents have a right to expect that their opinions will be encouraged, considered, and valued without being perceived as overbearing. Parent views should be recognized as part of the solution to issues, not part of the problem.
- Parents have a right to question programs, placements, and behavior modifying procedures as they apply to their son or daughter.
- Parents have a right to expect recognition of the expertise accumulated over their years of raising their son or daughter, and there should be reduction of the needless distinction between staff and parents.
- Parents have a right to expect their son or daughter will be in an environment that provides protection, support, and supervision as needed.
- Parents have a right to expect open communication channels and information sharing among program participants, parents, and staff.
- Parents have a right to expect to be involved in the medical well-being of their son or daughter and be kept informed of the medication, medical needs, and psychological programming of their sons and daughters.
- Parents have a right to expect to be given program information, orientation, and assistance when their son or daughter enters an agency or school.
- Parents have a right to expect that programs will work toward developing an individual's level of independence, consistent with abilities, which would lead to relationships with the parents similar to those between parents and other family members.

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* The philosophy involved in this document applies to other family advocates also.

TECHNICAL ASSISTANCE AVAILABLE FOR EARLY INTERVENTION PROGRAMS

Project Dakota Outreach has been awarded three-year funding from the U.S. Department of Education to assist Minnesota early intervention programs in developing family centered, community based services. Parents, programs, related agencies, and interagency groups may request assistance from the Project staff. Regional and statewide groups may also call on the Project for presentations on services to children from birth to age five. For more information, contact: Linda Kjerland or Jean Mendenhall; Project Dakota Outreach; 680 O'Neill Drive; Eagan, MN 55121. Tel. (612) 455-2335.

ASSISTANCE REQUESTED FROM PARENT TO PARENT NATIONAL SURVEY PROJECT

The Beach Center on Families and Disability, A Research and Training Center at the University of Kansas, is conducting a national survey of parent support groups that are implementing the Parent to Parent model of providing support to families who have a member with a disability. Parent to Parent programs serve special needs families by: (1) match- ing a "veteran" parent who is experienced in caring for a family member who has a disability with a "referred" parent who is new to the role, and (2) by providing emotional and informational support to the referred parents through this match.

"We want to find as many programs as possible and encourage them to share information and materials as a part of our survey process," said Project Coordinator, Betsy Santelli. As this information is compiled and made available to families and professionals, a national network could be established that can help programs learn from each other and assist new groups with start-up tasks.

Programs that use the parent to parent approach are asked to call or write: Betsy Santelli, Coordinator, or Ann Turnbull, Co-Director; Parent to Parent National Survey Project; Beach Center on Families and Disability, Bureau of Child Research, 4138 Haworth Hall, University of Kansas, Lawrence, Kansas 66045-2330. Tel. (913) 864-4950.

PUBLICATIONS AND RESOURCES

Supported Employment Implementation Issues: A Summary of Discussions from Virginia Commonwealth University, Research and Training Center, M. Barcus, S. Griffin, D. Mank, L. Rhodes, and S. Moon (Eds.), 1988. This document summarizes the discussions that took place in May 1988 at the "Supported Employment Implementation Issues" forum when approximately 100 professionals and advocates came together from around the country to discuss: 1) systems change/ conversion; 2) integration and empowerment; 3) in-state economic development and marketing; 4) long-term funding; and 5) technical assistance and staff development. Copies may be purchased for $13.95, payable to: Virginia Commonwealth University--Rehabilition Research and Training Center; ATTN: Anny Morgan Tysiak; Box 2011; Richmond, Virgnia 23284-2011. Tel. (804) 367-1851.

Generalization for Students with Severe Handicaps: Strategies and Solutions, Norris G. Haring, (Ed.), University of Washington Press, 1988. Students with severe handicaps often experience great difficulty in transferring skills learned at school to nonschool situations. If skills do not generalize to new and untrained situations, the student will need to be retaught that skill in every setting and every situation throughout life. This document offers educators some special strategies to ensure that skills are generalized to other situations. One strategy proposed is a decision rule system to assist educators in selecting appropriate remedial methods when a generalization problem is revealed. The strategies presented have been validated by public school teachers of students with moderate, severe, and profound handicaps. Copies may be purchased for $20.00 from: University of Washington Press, Order Department; P.O. Box 50096; Seattle, Washington 98145-5096. Tel. (206) 543-4050.

CASE MANAGEMENT CONFERENCE ANNOUNCED

The Third Case Management Conference sponsored by the Minnesota Department of Human Services and the Institute on Community Integration (formerly known as Minnesota University Affiliated Program on Developmental Disabilities) will be held **April 18 and 19, 1989** at the Thunderbird Motel in Bloomington, Minnesota. Featured speakers will include Beth Mount from West Hartford, Connecticut and Jerry Provencal, director of the Macomb-Oakland Regional Center in Michigan.

The conference theme will be **"Tailoring the System to Meet Individual Needs,"** and will address issues of process, progress, and futures planning. Personnel in human service agencies serving individuals with developmental disabilities, parents, and other interested persons are invited to participate in the conference. Pre-registration will be required. Brochures will be sent in early spring defining the conference program and registration costs. In order to place your name on the mailing list, contact: Ralph McQuarter; Department of Human Services; 444 Lafayette Road; St. Paul, MN 55155. Tel. (612) 296-2160.

REGIONAL WORKSHOPS ON TRANSITION OFFERED

During March and April, the Minnesota Deparment of Education and the Institute on Community Integration will present regional workshops on the transition of youth with disabilities from school to adult living. Entitled, "Leadership in Implementing State Transition Legislation," the workshops are designed for secondary teachers and administrators in special and vocational education and for chairpersons and others participating on Community Transition Interagency Committees. The dates and locations of the workshops are:

Mankato	March 9, 1989
Bemidji	March 14, 1989
St. Cloud	March 15, 1989
South Metro	April 18, 1989

For further information, call Sandy Thompson, CTIC Project Coordinator, at (612) 625-3863.

SEMINARS ON DEVELOPMENTAL DISABILITIES SCHEDULED

The Minnesota Institute on Community Integration (formerly called University Affiliated Program on Developmental Disabilities) has coordinated a series of Joint Training Grant Seminars. Speakers are members of the faculty of the University of Minnesota. The sessions will be held **Friday afternoons from 2:30 p.m. to 4:00 p.m. in Room 214, Pattee Hall, 150 Pillsbury Drive, S.E., Minneapolis (on the east bank at the University of Minnesota)**. These seminars are open to the public and are free of charge:

March 3, 1989
Residential Facilities: Is Smaller Always Better? Charlie K. Lakin from Educational Psychology Department;

April 12, 1989
Working in the Community: For Fun or Profit? David R. Johnson, Educational Psychology Department;

May 19, 1989
Conducting Group Design Research in the Field: Its Importance and the Reality of Making it Work, James Ysseldyke and Martha Thurlow, Education Psychology Department;

June 2, 1989Conducting Basic Research in Applied Settings: Can it Be Done and Is It Important? Scott McConnell, Educational Psychology Department, and Celia Wolk- Gershenson, Psychology Department.

For further information, please call (612) 624-4848.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.**

LENDING LIBRARY SELECTIONS

They Don't Come with Manuals, (VHS 1/2 inch videotape, 20 minutes), produced by Community Services Information Group for the Louisiana Division of Children, Youth and Family Services, 1988. Adoptive and foster parents share their experiences as parents of children who have disabilities. The importance and advantages of children growing up in permanent homes is stressed.

Proceedings of the First National Fragile X Conference, presented by the Fragile X Foundation (December 3 & 4, 1987), Denver Colorado. This two-volume set of 13 audio tapes includes selected presentations that occurred at the First National Fragile X Conference in 1987. Examples of some of these presentations include: "Fragile X: The Present State of Knowledge" by John M. Opitz, M.D.; "Psychological and Behavioral Aspects of Fragile X," by Andrew Levitas, M.D.; "After the Diagnosis: A Parent Discussion Group," led by Jeannie Lancaster; and "Inheritance of the Fragile X Syndrome," by Stephanie Serman.

Job Match: Together for Good Business, a Multimedia Training Kit, produced by Floyd T. Waterman, Ph.D., Director of the Center for Applied Urban Research, University of Nebraska at Omaha (February 1987). This kit consists of two audio tapes and one videotape (VHS 1/2 inch, 20 minutes). This multimedia training kit is intended for employers and employing agencies for the purpose of increasing employment opportunities for the vast and valuable pool of individuals with special needs who are available and qualified for work. Emphasis is placed upon how partnerships between employers and human service agencies can be fostered.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

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D D INFORMATION EXCHANGE

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1989 AGENDA
SHARING A LIFE TOGETHER

Bev had been home an hour or so from her job and had been cleaning up the apartment by vacuuming the carpet and using pine-scented disinfectant on some of the counters. Her husband, Art, was due home from his job about 4 p.m. With the cleaning finished, Bev sat and talked about her life and some of her experiences. Art joined her later.

Bev, who is 59, and Art, who is 60, have been married four and a half years. Like many people they are active in their community. They have joined the Presbyterian church in their city of Red Wing and attend church every Sunday. Both work full time but in the evenings and on weekends they go for walks around town, go to movies, out for coffee, or out to dinner. Sometimes they go to friends to visit or friends come to see them. Bev has a hobby of latchhooking and makes pillows and rugs as gifts and to sell. All her designs are colorful originals she creates while she works on them. Occasionally they take an interest in the city's affairs and attend city council meetings where they will sometimes offer their opinions on the problems and issues concerning city operations.

Like most married couples, Bev and Art have a division of duties around the apartment based on what their preferences and talents are. Art does the weekly laundry on Friday evenings and claims to be a pretty good cook. Bev does the cleaning and likes to spend money. Conservative Art puts the clamps on when she starts buying. They do grocery and other shopping together. While Bev likes to go out a lot, Art is a homebody and prefers to stay in the snug apartment, so each compromises a little for the other.

Together Bev and Art live regular lives in their town of Red Wing. But it wasn't always so regular for either of them. Both of them have developmental disabilities. Both of them have mental retardation, and Art also has epilepsy for which he take daily medication. Art is also under state guardianship. Their success in living regular lives has come about because of their love for each other and their determination to live on their own.

Bev grew up on her aunt's farm near Red Wing. She went to school through the eighth grade and then helped around the farm on various tasks. Chopping wood with a wedge and hammer for their woodstove was one chore she was responsible for. When Bev's aunt died after a long illness, Bev was moved to a group home in Red Wing in 1983. After living with her family her entire life, she now lived with 14 strangers.

Art also lived with his family during his childhood and as an adult with the exception of several years when he lived in Cambridge State Hospital. Art's father worked at the sawmill in town and took Art to work with him every day. Art drove the tractor at the sawmill. When Art's parents died, Art was moved to a group home in Red Wing. After living with his family his entire life, he now lived with 14 strangers.

It was in the group home that Bev and Art met each other and eventually fell in love. Art was afraid that Bev was going to move out, because staff were talking to her about that possibility. Art didn't want to lose Bev, so he asked her to marry him. Together, they went to Art's case manager, Nancy Kasa, in Goodhue county and told her of their desires and plans.

Kasa was delighted with their decision and promised to take care of the necessary paper work to make their dreams possible. Not everyone was so happy over their plans. How could two people with mental retardation live independently? What about Art's daily medication?

However, the permission was received, and Art and Bev proceeded with their wedding plans.

The wedding went like most weddings. The wedding announcement and picture of the two of them was in the local paper. Nancy, Bev's best friend, held a shower for her where she received lots of gifts. The invitations were addressed and mailed by Bev herself. About 50 people attended the wedding ceremony on a Saturday in December 1984, in the Methodist church in Red Wing. Following the ceremony they celebrated with a dinner and dance with family and friends at Butch's Ballroom. Two albums of photos contain the evidence of a memorable and happy occasion.

Their comfortable one-bedroom apartment is in a remodeled mansion. Decorated in browns and golds, it has a lived-in look and feel. Afghans cover the chairs. There are lots of knick knacks and plants around, and shutters on the windows. Art doesn't read so the push-button telephone is color-coded. His system for taking his daily medications is also color-coded. Initially they had daily assistance from a Semi-Independent Living Services (SILS) provider, but now it's only every other day or about eight hours a week.

Art refers to the group home as "that place down there." In comparing the two places, he says that now he wakes up to a clock radio instead of a staff person yelling at him. In the group home he couldn't ever go out unless staff went with him; now he goes out whenever he wants. He claims he also cooks bacon better than the group home staff. They go to the doctor when they want or need to and not because it's scheduled. Bev complained that she didn't get enough to eat for breakfast to last her for the morning. Both agree that the food they fix for themselves is better than before.

When one sees the two of them together, it is obvious that they are happy and in love, and that they care a great deal for each other. They chose to live together because they wanted to and not with 13 strangers.

Way to go, Bev and Art

RECREATION

Fifth Annual SILS Dance

A springtime dance for individuals in independent and/or semi-independent living situations (SILS) will be held on Friday, May 19. Pillsbury House and Southside Services are sponsoring the dance for the fifth time. The dance will be held at the Falldin American Legion Post 555, 3141 Central Av. NE, Minneapolis, from 7 to 10 p.m. A nominal entrance fee will be charged. Free food, door prizes and band music will be offered. Flyers will be mailed to all SILS providers in the Twin Cities area to distribute to their residents. For more information, contact Jerry or Rich at Southside Services 721-1696.

Sensory Integration Summer Camp

AVANT-Camp St. Croix is a program combining an intensive sensory integration treatment approach with a rustic and challenging camp environment. The camp is designed for boys and girls aged 6-13 who have average or above average intelligence, but who have learning disabilities and/or sensory integrative dysfunction, including poor coordination, hyperactivity, poor attention or inadequate motor planning skills. The camp will be June 11-17. The fee is $250. Scholarships are available. For more information contact: Eileen Richter, Research and Development in Pediatric Therapy, Inc., 12015 N. July Av., Hugo, MN 55038 or (612) 439-8865.

Eden Wood Camping and Retreat Center

Eden Wood Camping and Retreat Center in Eden Prairie is offering a variety of camping options, including leisure specialties, creative arts and kids' week sessions, as well as trips to the Boundary Waters, state parks and lake cabins. Adult vacations include trips to the Wisconsin Dells, the Black Hills and Yellowstone National Park. Specialty weekends offer canoeing, family camp and respite care for any age participant. Program fees range from $250 to $275 for most week-long sessions. Brochures and registration information are available from the ARC Hennepin County, 2344 Nicollet Av. S., Minneapolis, MN 55404; (612) 874-6650.

BOOKS

Toward Supported Employment--A Process Guide for Planned Change by James F. Gardner, Ph.D., Michael S. Chapman, M.Ed., Gary Donaldson, M.Ed., and Solomon G. Jacobson, Ph.D.

This book is a clear, easy-to-follow guide that provides hands-on information for facilitating the change from a segregated work activity program to a supported work program. It introduces the key elements of change, identifies change-related variables that must be controlled, and defines the roles and responsibilities of management and key staff.

The authors, who managed one of the Office of Special Education and Rehabilitation (OSER) demonstration projects in supported employment, believe that the success of supported-employment conversion is based on three well- defined values. First, faith in integrated work for persons with severe disabilities must precede all other values and commitments. Second, the conversion to supported employment must proceed regardless of whether the agency has all the answers and guarantees it would like. Third, supported employment conversion must be understood as a form of planned change requiring the ability and resources to manage a complex change process.

The first four chapters set a conceptual framework by introducing the elements of change, identifying variables that must be controlled, and defining roles for management and key staff. Chapters 5 and 6 discuss readiness factors and leadership styles necessary. Chapter 7 discusses supported employment as a business enterprise and the structures necessary for it to be a success. Coordination of employment services with other human services is the topic of Chapter 8. Chapter 9 covers management controls, and the final chapter discusses the future of supported employment.

The book may be purchased from Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285. The cost is $18.00 and the order number is #000X.

For people who live in the Metro Area, this book may be borrowed from the DD Library at the Metropolitan Council. The book must be picked up.

The Handbook of Drugs for Children with Special Needs by Dianne L Eberlein, R.Ph.

This book is written particularly for parents and teachers in easy to understand language. It gives valuable information about the drugs prescribed to children with special needs such as epilepsy, attention deficit hyperactivity disorder, Tourettes' Syndrome, and autism.

The first chapter explains how to calculate drug doses for children and how to interpret prescription directions, and provides some basic pharmacology. The last three chapters explain the use--and misuse--of anticonvulsants, stimulants and antipsychotics. Throughout the book, medical terminology is used sparingly and analogies are used freely. A Drug Diary and Test Record are also included for use by parents.

The book is available for $15.79 (includes sales tax and postage) from Drugwise Communications, Attn: Dianne Eberlein, 513 Second Av. SE., Minneapolis, MN 55414.

It's Never Too Early, It's Never Too Late by Beth Mount and Kay Zwernik

The Metropolitan Council has published a guidebook for people with developmental disabilities, their families and their advocates.

It's Never Too Early, It's Never Too Late is an introduction to personal futures planning, a process that focuses on people's gifts, talents and abilities rather than their deficiencies. It provides strategies for people with developmental disabilities to develop personal relationships, have positive roles in community life, increase their control of their own lives, and develop skills and abilities to achieve these goals.

A personal futures plan is a person's vision for what he or she would like to be and do, and represents an active plan for making changes to realize the vision. It becomes an ongoing problem-solving process, and is accomplished through a small group of people who agree to meet for mutual support, brainstorming and strategizing. This circle of support or person-centered team makes commitments and takes action to ensure that changes will be accomplished for the focus person.

From one to five copies are available to Metro Area residents free from the Metropolitan Council's Data Center, Mears Park Centre, 230 E. Fifth St., St. Paul, MN 55101. Larger quantities and copies for residents of Greater Minnesota may be obtained from the Governor's Planning Council on Developmental Disabilities, 300 Centennial Bldg., 658 Cedar St., St. Paul, MN 55155.

WORKSHOPS/CONFERENCES

April Dates, 1989

Early intervention services are the focus of a series of statewide workshops sponsored by Parent Advocacy Coalition for Educational Rights (PACER). The workshops are for parents of infants, toddlers and pre-schoolers with special needs. Parents will meet other parents, hear how the system works, gain tips on how to get good services for their child, learn about assessment and the Individual Education Plan (IEP), and learn how to communicate with professionals. All workshops are free and run from 7 to 9:30 p.m. They will be at the following locations

- April 6 Best Western Garden Inn
  Hwy.way 169 North Mankato, MN

- April 11 Whitney Senior Center
  1125 Northway Dr. St. Cloud, MN

- April 13 Reuben Lindh Learning Center
  3616 12th Av. S. Minneapolis MN

- April 17 Best Western Summit
  Room A Hwy. 32 S. Thief River Falls, MN

- April 18 Holiday Inn
  Hwy. 2 W. Bemidji, MN

April 6, 13, 20, 27

"Aging and Developmental Disabilities: Moral, Ethical and Legal Issues" is the topic for a series of videotape/teleconference programs to discuss issues related to elderly persons with developmental disabilities Sponsored by the Institute on Community Integration, they will be held on Thursdays in April from 2 to 4 p.m. in the Discourse Room, Second Floor, Pattee Hall, University of Minnesota, 150 Pillsbury Dr. SE., Minneapolis, MN. All sessions are free. Reservations are preferred because of limited seating. Call (612) 624-7879.

April 6 "Aging: A Shared Experience"--themes of integration and friendship; helping families and service providers meet their needs.

April 13 "I Should Know a Lot, I Been Around So Long"--stories of persons with mental retardation who have lived long lives; past, present and future decision-making.

April 20 "Rights of the Older Person with Developmental Disabilities"--Older Americans Act of 1987, DD Act of 1987 and Nursing Home Reform Act of 1988.

April 27 "That's What Friends Are For"--the powerful force of friendships on participation in the community.

April 8, 1989

Parent Advocacy Coalition for Educational Rights (PACER) Integration Workshop is for parents of children with special needs, regular and special educators, and other community builders. It will be at the Radisson University Hotel, 615 Washington Av. SE., Minneapolis, MN, from 9 a.m. to 3 p.m. Speakers will include Barbara Buswell, founder of PEAK Parent Center, Colorado Springs, CO; Larry Ringer, attorney with Legal Advocacy for the Developmentally Disabled of Minnesota; and Cathleen Meyer, a student with a hearing impairment. The program will cover the meaning of LRE (Least Restrictive Environment), using the Individual Education Process (IEP) process to make integration happen, promoting friendships, and preparing a school to integrate kids with challenging needs. Fee of $6.00 includes lunch. To register, call PACER at (612) 827-2966.

April 8, 1989

"Individual Habilitation Planning: The Process and Product" will be held at the United Way Multi-Service Center, 14451 County Rd. 11, Burnsville, MN, from 9 a.m. to 2:30 p.m. Sponsored by the ARC Suburban, the workshop will cover what an IHP is, how it relates to ISP, IEP, IPP and IFSP, what it looks like and who writes it, appropriate goals and objectives, and how to insure quality and accountability. The charge is $5 for ARC members and $12 for non members. Lunch is included. To register call the ARC office at (612) 431-3700.

April 11 and 18, 1989

The Minnesota Department of Education and the Institute on Community Integration are sponsoring two seminars in the Metro Area on developing leadership in implementing state transition legislation. The seminar on April 11 will be at the Shoreview Holiday Inn, and that on April 18th will be at the Burnsville Holiday Inn. Both are from 9 a.m. to 3 p.m. with a fee of $20. Topics covered include Community Transition Interagency Committee Leadership training, Special Education and Vocational Education Cooperative Planning Guide, and transition planning for secondary students in special education. Send registration fee to: Sandy Thompson, Institute on Community Integration, Rm. 6, Pattee Hall, 150 Pillsbury Dr. SE., Minneapolis, MN 55455. For more information call Sandy at (612) 625-3863.

April 22-23, 1989

The Epilepsy Education program of the University of Minesota is sponsoring a two-day workshop on the "Sepulveda Epilepsy Education Program (SEE)." The speaker will be Robert J. Mittan, Ph.D., who started this program based upon his research when he was at the Sepulveda VA Hospital. Dr. Mittan is currently director of the depts. of neuropsychology and psychology at the Charlotte, N.C.Mecklenburg Hospital. The first day of the workshop will cover what epilepsy is and how it is treated; the second day will cover coping with social and emotional problems connected with epilepsy. The fees are $25 for one day and $40 for two days for professionals and $15 and $25 for people with epilepsy and their families. The workshop will be held at Willey Hall, 225 19th Av. S., at the University of Minnesota. For further information, contact: Deb McNally, Epilepsy Education, University of Minnesota, 2701 University Av. SE.,Minneapolis, MN 55414. Call (612) 331-4477 or (800) 292-2932 toll free.

April 29, 1989

The 2nd Annual Adaptive Devices Conference will be held at the Willmar Junior High School in Willmar, MN, from 8:30 a.m. to 3 p.m. The keynote address will be given by Rick Creech, a well-known advocate of paravocal communication and independent living and an expert paravocal communicator. Sessions will be conducted by 15 presenters on technology and resources presently being utilized throughtout the state at home, work and play. The fees are $35 for SW/WC ECSU members, $50 for registrants outside Regions 6 & 8, and $15 for parents of students with disabilities. For registration forms contact: Pat Eklof, SW/WC ECSU Teacher Center, P.O. Box 547, Marshall, MN 56258.

May 6, 1989

"Celebrate and Challenge" is a workshop for parents of children and adults with disabilities to discuss what Catholic religious services should be expanded or implemented. It will be held at Mary, Mother of the Church, 3333 Cliff Rd., Burnsvile, MN, from 9:30 a.m. to 3 p.m. The day will include discussion groups, and panels of persons with disabilities and parents who have children with disabilities speaking on their church experiences. Representatives from the Archdiocesan church will be present to hear what parents have to say. The fee is $7.50 for one or $14 for a couple, including lunch. For registration forms or more information, call: Brigid O'Connell at 291-4519 or Sue Bitney at 623-4019. TDD: 378-1344.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
April 1989

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300 Centennial Office Building
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
612/296-4018

**Member of
National Association of
Developmental Disabilities
Councils**

NEW RESEARCH EFFORT LOOKS AT POSITIVE CONTRIBUTIONS BY CHILDREN WITH DISABILITIES[1]

As observed by Ann P. Turnbull, codirector of the Beach Center on Families and Disability at the University of Kansas, it is only recently that there have been any published writings by professionals to suggest that children with disabilities have **positive** as well as negative impacts on their families. After reviewing past professional literature, Turnbull concluded that there was minimal indication that persons with disabilities make positive contributions. "On the contrary," she observed, "a negative bias frequently exists. Where is the writing of professionals about the positive contributions that persons with disabilities have made to their lives? If actions are the by-products of values, what does a negative focus imply about our interpretations of the meaning of disability?"

Turnbull identified two types of biasing statements in the literature. "The first is a pervasive negative generalization," she stated giving the following example:

> In most families in which there is a defective member, pervasive guilt permeates the family and is experessed in its characteristic style. The birth of a retarded child, his presence in the home, and even the knowlege that such a child once lived at home, greatly exacerbates this existential guilt. (Martino & Newman, 1974, Child Psychiatry and Human Development, p. 168.)

A second type of bias occurs when researchers explain unexpected positive findings through a negative interpretation, such as:

> Jacobs (1969) . . . found that most of the normal brothers and sisters of a group of retarded children were sympathetic, helpful, and understanding and did not seem to have been adversely affected by their mentally retarded siblings. It is quite possible, however, that these siblings were outwardly helpful and cooperative while manifesting adjustment problems in other ways. (Wasserman, 1983, Identifying the counseling needs of the siblings of mentally retarded children. Personnel and Guidance Journal, p. 622.)

"A final issue," Turnbull added, "is the assumption that appears to operate among professionals that children without disabilites are easy to raise and children with disabilities are a burden." For example, one mother of three children commented, "At times, Jay, our son with mental retardation, is the easiest; other times he is the most stressful. Sometimes I long for his bright and active sisters to follow his lead in many areas--he has never whined in his life, has never said 'yuk' at mealtime, and has never said an unkind word about anyone."

The negative bias from the moment of earliest interactions was related by a father as follows:

> When normal children are born, the doctors do not recount for parents all the problems that could happen to their child, like drug involvement, flunking out of college, sexual promiscuity, or teenage suicide; however, when a child with Down syndrome is born, the doctors only point out the negative.

A research project has been initiated at the University of Kansas to investigate positive contributions. One of the first studies was an attempt to analyze letters to Congress written by parents, relatives, and individuals with disabilites to comment on the 1983 proposed regulations concerning the medical treatment of newborn infants with disabilities. Six types of positive contributions were identified: the person with the disability being a source of happiness, a source of love, a source of learning life's lessons, a source of blessing or fulfillment, a source of pride, and a source of strength.

Turnbull provided one quote to illustrate the category of learning life's lessons:

> Our life and the lives of our family were changed forever on January 18, 1980. At about 6:00 p.m. our daughter Sarah was born. She weighed three pounds. Her diagnosis from the doctor was hopeless--twenty-four hours to live, deaf, blind, severely retarded.
>
> As I looked at her fighting to live, held her in the palms of my hands, amazed that this little one was my daughter, hope became eternal for me.
>
> In the next twenty-six months she taught us more about love, courage, faith and life than most of us can teach or learn in a hundred years.

"I believe that this research is important for two major reasons," Tunbull continued. "First, it has the potential of decreasing the stigma that occurs when persons are viewed as wholly negative. Secondly, research in this area has the potential for providing intervention strategies aimed at supporting persons with disabilities and their families to accentuate the positive aspects of their circumstance."

Ultimately," Turnbull added, "my colleagues and I believe that the phenomenon of positive contributions . . . represents an important component of personal growth through meeting the challenge of difficult circumstances. We were struck by the comment of an individual with a disability in his letter on the treatment regulations, 'It (the disability) is the greatest thing that has happened to me. For without these limitations, I would not have been able to acquire some of the important character qualities of life.'"

"Consistent to this theme," Turnbull continued, "are the insights of persons who have encountered other types of limitations. We remember President Kennedy's reply to the question, 'How did you become a war hero?' He said, 'It was involuntary. They sunk my boat.'"

In summary, Turnbull closed with a quote of Clara Claiborne Park (The Siege: The First Eight Years of an Autistic Child, 1982):

> I do not forget the pain--it aches in a particular way when I look at Jessy's friends, some of them just her age, and allow myself for a moment to think of all she cannot be. But we cannot sift experience and take only the part that does not hurt us... Through it we have learned the lesson that no one studies willingly, the hard, slow lesson of Sophocles and Shakespeare--that one grows by suffering. And that too is Jessy's gift. I write now what fifteen years past I would still not have thought possible to write: that if today I were given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands--because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love (p. 320).

"I urge you to join in the effort of supporting families to identify and capitalize upon the positive contibutions of their children with disabilities. By so doing, you can increase the likelihood that the last word of their family story will also be love," Turnbull concluded.

MAINE ESTABLISHES ASSISTIVE TECHNOLOGY LOAN FUND

Maine became the first state in the country to establish an assistive technology loan fund through a bond referendum in last November's election. The five million dollar, self-perpetuating, revolving loan fund will make it possible for citizens with disabilities and businesses to obtain low interest loans to purchase needed assistive technology devices. The Finance Authority of Maine will establish a nine-member board, including five members who have diabilities, to develop guidelines. Each loan will be considered on an individual basis based on need and credit-worthiness.

This creative bond issue was spearheaded by Alpha One, a Center for Independent Living. The Center established a committee to travel the state to obtain endorsements from newspapers and organizations and develop grassroots support for the bond referendum. Only a few weeks after passage of the bond referendum, the Alpha One Center has received numerous phone calls requesting information on how to apply. For more information, contact: Janet Lamoreau at Alpha One (207) 767-2189.

TOLL-FREE TELEPHONE SERVICES IN THE UNITED STATES

American Association on Mental Retardation	1-800-424-3688
American Council of the Blind	1-800-424-8666
American Diabetes Association	1-800-232-3472
American Foundation for the Blind	1-800-232-5463
American Paralysis Association	1-800-225-1292
Association for Retarded Citizens of the US	1-800-433-5255
Better Hearing Institute Helpline	1-800-424-8576
Captioned Films for the Deaf	1-800-237-6213
Center for Special Education Technology Information Exchange	1-800-345-8324
Epilepsy Foundation of America	1-800-332-1000
HEATH (Higher Education & the Handicapped Resource Center	1-800-54-HEATH
Job Accommodation Network	1-800-526-7234
Job Opportunities for the Blind	1-800-638-7518
National Alliance of Blind Students	1-800-424-8666
National Association for Hearing & Speech Action (V/TDD)	1-800-638-8255
National Association for Parents of the Visually Impaired	1-800-562-6265
National Child Abuse Hotline	1-800-4-A-CHILD
National Committee for Citizens in Education	1-800-NETWORK
National Down Syndrome Congress	1-800-232-6372
National Down Syndrome Society	1-800-221-4602
National Easter Seal Society	1-800-221-6827
National Head Injury Foundation	1-800-444-NHIF
National Health Information Clearinghouse	1-800-336-4797
National Information Center on Deaf-Blindness	1-800-672-6720

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[1] This article highlights a chapter contributed by Ann P. Turnbull in Strengthing Families: New Directions in Providing Services to People with Developmental Disabilities and Their Families, Levy, J. M., Levy P. H., & Nivin, B. (Eds.), (1989), which may be purchased from the publisher, Young Adult Institute Press, 460 West 34th Street, New York, NY 10001. Tel. (212) 563-7474.

National Information System for Health Related Services	1-800-922-9234
National Organization on Disability	1-800-248-ABLE
National Rehabilitation Information Center	(V/TDD)1-800-34-NARIC
National Special Needs Center	(TDD)1-800-833-3232 1-800-233-1222
Resource Center for the Handicapped	1-800-22-SHARE
Retinitis Pigmentosa Association	1-800-344-4877
Retinitis Pigmentosa Foundation Fighting Blindness	1-800-638-2300
Social Security Administration	1-800-234-5772

PUBLICATIONS

The Data Book: Special Education in Minnesota, Minnesota Department of Education, January 1989. This is a valuable reference using graphs and charts describing the educational opportunities for learners with disabilities in Minnesota. There has been growth in the expenditures and essential staff needed to support specialized services to students with disabilities. However, state commitment to special education, in terms of the provision of state special education aid, has declined in recent years placing more of the burden of the cost on the local school district. Data also varifies that Minnesota falls behind national averages in providing special educational services in the least restrictive (non-segregated) settings. Copies for people residing in Minnesota cost $5.50. The charge to people living outside of Minnesota is $8.00. Order number "B-602" from: Minnesota Curriculum Services Center; 3554 White Bear Avenue; White Bear Lake, MN 55110. Tel. (612) 770-3943, or (800) 652-9024 toll-free from within the State.

SUMMER INSTITUTE ON INTEGRATED EDUCATION OFFERED IN CANADA: AN OPPORTUNITY FOR STUDY AND TRAVEL

The Canadian Association for Community Living and the G. Allan Roeher Institute, in cooperation with four universities, will be sponsoring the 1989 Summer Institute in Integrated Education for two, intensive weeks in July 1989. Learn how to include children with special needs in regular classrooms, make them a welcome part of a school community, develop and adapt curriculum, and build circles of friends. There are four locations from which to choose: McGill University in Montreal, Quebec; Acadia University, School of Education in Wolfville, Nova Scotia; University of British Columbia; and Lethbridge University, in Lethbridge, Alberta. Some of the faculty include: Marsha Forest, Judith Snow, Evelyn Lusthaus, George Flynn, Herb Lovett, John Mcknight, Alison Ford, Jan Nisbet, John O'Brien, Diane Ferguson, Michael Giangreco, and Donald Little.

Applications are due before April 30, 1989. For further information, contact: Judith Butler, the G. Allan Roeher Institute; York University Campus; 4700 Keele Street; Downsview, Ontario M3J 1P3. Tel. (416) 661-9611.

CONFERENCES/WORKSHOPS

Correction

In the March issue of DD Information Exchange--State Supplement, "Seminars on Developmental Disabilities Scheduled," (page 7), there was an incorrect date printed. Please note that the seminar "Working in the Community:
For Fun or Profit?" at Pattee Hall, Institute on Community Integration, University of Minnesota, will be offered on **April 21, 1989**, not April 12. For further information, call: (612) 624-4848.

April 28, 1989

"Up the Mainstream without a Paddle? The Regular Education Initiative" is the theme of a conference that will be sponsored by the Minnesota Council for Exceptional Children and the Minnesota Council for Children with Behavioral Disabilities. It will be held at the Radisson Hotel South, Bloomington, Minnesota (Highways 494 and 100). The keynote speaker will be James Kaufman, Ph.D., University of Virginia. For more information, call Eunice Dinga: (218) 299-2200, ext. 573 (work); or (218) 233-6024.

May 15, 1989--College of St. Catherine, St. Paul, MN
May 17, 1989--Mankato Technical Institute, Mankato, MN
May 19, 1989--Sawmill Inn, Grand Rapids, MN

On the above dates, **"Identifying Chemical Abuse in Special Populations: Older Adults, Persons with Physical Disabilities, and Persons with Mental Illness"** will be offered by Hazelden. This workshop will enable helping professionals to identify and screen for possible chemical abuse and dependency. For information, call: (612) 462-7700, ext. 2519 (toll free Metro Area), or (612) 257-4010, ext. 2519 (Minnesota).

May 17-20, 1989

"Capitol Challenges . . . A New Era" is the theme of the 1989 United Cerebral Palsy Associations Conference and Annual Meeting that will be held at the Radisson Mark Plaza Hotel, Alexandria, Virginia and Capitol Hill in Washington, DC. For more information and registration, contact: UCPA; Community Services Division; 1522 K Street, NW; Washington, DC 20005. Tel. 1 (800) USA-5UCP (toll free).

June 21-23, 1989

"Shine on Minnesota" is the theme of the Summer Training Conference at Madden's on Gull Lake, Brainerd, Minnesota. This conference is sponsored by Minnesota Developmental Achievement Center Association, Minnesota Association of Rehabilitation Facilities, and Staples Technical Institute. For registration and more information, contact: 1989 Summer Training Conference; 1821 University Avenue, 376-South; St. Paul, MN 55104. Tel. MARF (612) 646 0900; MnDACA (612) 647-9200.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.**

LENDING LIBRARY SELECTIONS

__With a Little Help from My Friends__, is a new one-hour videotape about creating schools where all students belong and learn together. It was produced by Marsha Forest and George Flynn. Three sections include: 1) "The Vision"-- Judith Snow, Marsha Forest, and the students and staff of St. Francis School, Waterloo Region Separate School Board, Kitchener, Ontario; 2) "Let's Talk"--students and staff discuss what integration has meant to them; and 3) "May's Map"--an example of planning curriculum that builds schools that are inclusive. "Just watch these kids, said Robert and Martha Perske from Connecticut, "and listen to their wisdom. They possess the wisdom for a new age." This videotape is also available for purchase: price is $50.00, plus $5.00 shipping, from: Expectations Unlimited; P.O. Box 655; Niwot, Colorado 80544. Tel. (303) 652-2727.

The following two selections are available on one videotape cassette (VHS 1/2 inch):

__A Normal Life__ (20 minutes), produced by the Minnesota Department of Human Services, 1989. This production chronicles the progress of group homes operated by Minnesota regional treatment centers. It includes interviews with employees, residents, parents, and an employee of one of the residences.

__In the Sunshine__ (14 minutes), produced by the Association for Retarded Citizens of Minnesota, 1989. Filmed in various locations in Minnesota, this production depicts the quality of life for individuals with multiple disabilities who have moved from state operated regional treatment centers to homes in community settings. Parents testify that their sons and daughters are "better off," get closer supervision, have more opportunities to make choices, and are more involved by doing things for themselves.

Metropolitan Council DD Program
Mears Park Centre
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St. Paul, MN 55101

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INFORMATION EXCHANGE

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Editor: Kay Zwernik

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1989 AGENDA ACCOMPLISHMENT

OUT AND ABOUT

Mary is out and about and active in her Shoreview community, in Ramsey County. She is employed by Super 8 motels where she works as a housekeeper five days a week. She loves her job and says she works hard every day. When she is not at her job, Mary is on the go. A very social person, she loves group activities and just being with other people.

Every Tuesday evening she goes to a neighborhood ceramics class where she paints pre-cast items with seven other women who enjoy the comradery of this activity. Her pride in her finished work is astounding. Items with rabbits have been a definite favorite.

Mary also shops for groceries, personal items and her own clothes. She attends church, a religious education program, goes bowling and roller skating and goes to community education classes. You would never know it from looking at her petite body that her favorite thing to do is to go out to eat.

Mary takes particular pride in her personal appearance. Clothes are very important and selecting what to wear each day is done with great care and attention. Each morning her hair is curled since Mary knows how important it is to look neat at her job.

Things were not always like this for Mary O'Connell. Mary was born in 1950 with Down's Syndrome, a geetic disorder. At that time most people felt that people with Down's Syndrome had little future, little capacity to learn and to be productive. Mary's family was probably told this and upon the hospital's recommendation did not take her home from the hospital. Instead, 30 days later, she was place under state guardianship and spent the next 25 years of her life in two of Minnesota's regional treatment centers.

During her growing up years there was no public schooling for her so Mary never learned to read and write. There was no vocational program so Mary never learned to perform any kind of job activity. In the big dormitories there were no living rooms and kitchens, so Mary never learned to cook, or vacuum or do the laundry. Probably because of her social nature and a little feistiness, she survived the institution life.

In November of 1975 Mary left the institution and moved to Shoreview with a friend who lived there also. At that time Mary dressed and fed herself and spoke in single words, but she had few other skills. Life soon became a lot different for Mary and the other seven individuals with whom she lived. There was a real living room and a real kitchen and a bedroom with only one other roommate instead of more than a dozen.

Mary started a day program and began going out into the community on a regular basis. In four years her IQ doubled. She was no longer considered severely mentally retarded. Her acquisition of skills multiplied rapidly and her sense of accomplishment grew. Probably the most significant development for her was working. The job gave her status among her peers. The increase in her self- esteem became apparent as she exhibited greater self-confidence and pride in her accomplishments.

Mary is my friend and I am her legal guardian now. I too am proud of what Mary has done and who she has become. Together we are looking toward the future and even better things for Mary. She and I want Mary to have her own home, her own bedroom, more friends without disabilities, increased opportunities to make majcr decisions about her life, and the opportunities to spend the major part of each day with people who aren't staff and who don't have mental retardation.

Mary's friend, Kay Zwernik, Senior Planner, Developmental Disabilities Program, Metropolitan Council

FOR YOUR INFORMATION

Free Lifetime Parks Permit Available

The Golden Access Passport is a free lifetime entrance permit to parks, monuments and recreation areas administered by the federal government where entrance fees are charged. The passport is issued to citizens or permanent residents of the U.S. who have been medically determined to have blindness or a permanent disability and are receiving benefits provided under federal law.

The passport also provides a 50 percent discount of federal use fees charged for facilities such as camping, boat launching and parking. The Golden Access Passport admits the permit holder and a carload of accompanying people or, where entry is not provided by car, the permit holder, a spouse, children and parents.

Golden Access Passports may only be obtained in person and are available at most federally operated recreation areas. An individual must show medical proof of the permanent disability and receipt of benefits under federal law.

For further information about Golden Access Passports, contact the National Park Service, Midwestern Regional Office, 1709 Jackson St. Omaha, NE 68102, or phone (402) 221-3471. Also available are brochures of information on federal parks, monuments and recreation areas in each state. For specific parks and a listing of all national park sites, ask for "The Index."

Brochure on Integrated School Communities

The Minnesota Integrated Education Technical Assistance Project has prepared a new brochure listing 10 reasons why students with developmental disabilities should be integrated into school communities. Here's a synopsis of those reasons:

1. Preparation for adult living--The goal of education is to prepare individuals to be contributing members of society. By attending local schools, students with disabilities receive instruction in the communities where they live, practicing skills in the actual community settings where they're needed, gaining familiarity with the locale, and developing a sense of belonging.

2. Improved learning--Peers are often the best models and teachers of many socially valued behaviors, and in integrated settings, students with disabilities have opportunities to learn many things, including mobility, vocational, social, and communication, skills from students without disabilities.

3. Growth for peers--Through having students with disabilities in their schools and classes, peers without disabilities learn to develop skills in dealing with others who are different from themselves.

4. Effective use of resources--Special educators and regular educators support each other in meeing the educational needs of all children through collaboration.

5. Friendship development--Peer relationships between students with disabilities and classmates without are important now and in the future, and are essential to a successful and fulfilling life in the community.

6. Acceptance of differences--As students with and without disabilities interact as classmates and friends, their parents and teachers have the opportunity to witness successful integration in action...and it enables them to embrace the vision of a society that accepts and values the inclusion of persons with disabilities into all aspects of community life.

7. Team building--Greater collaboration between regular and special educators results in improved instruction for students and an increased "esprit de corps."

8. Individualized education--A good individualized program for a student with disabilities seeks to mesh with that of the student's peers while still meeting her/his individual educational needs.

9. Parental Involvement--Parents of integrated students can reach out for support from parents of other local students with disabilities, as well as from parents of same-age children without disabilities.

10. Support of Civil Rights--In a democratic society every person is to be afforded equal opportunities; segregated settings symbolize society's rejection of one segment of the population. Through participation in integrated schools and communities, students with and without disabilities can experience the richness of a society that values and includes all its citizens.

For copies of this brochure contact: Minnesota Integrated Education Technical Assistance Project, Institute on Community Integration, University of

Minnesota, 6 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455. (612) 624-4848.

Epilepsy Library Service

The National Epilepsy Library of the Epilepsy Foundation of America announces the introduction of a toll-free information service for use by physicians and other professionals. Librarians provide reference service by conducting customized literature searches of the comprehensive in-house data-base and library collection on medical and psychosocial aspects of epilepsy. For more information about National Epilepsy Library services or to request a library search, call the EFA National Epilepsy Library at (800) EFA-4050.

TASH Adopts New Resolutions

At the December 1988, Executive Board meeting of The Association for Persons with Severe Handicaps (TASH), two new resolutions were adopted: the Resolution on Choices and the Supported Education Resolution.

The Resolution on Choices was developed by the Adult Services Committee of the Minnesota Association for Persons with Severe Handicaps (MNASH), approved by the MNASH Board and forwarded to TASH for its consideration. It reads as follows:

Whereas, all people have preferences and express those choices in all aspects of their lives; and

Whereas, the natural opportunity for making choices begins early in life; and

Whereas, increased opportunities to express everyday preferences and choices can heighten an individual's sense of self-esteem and self-direction; and

Whereas, freedom of expression and choice are fundamental human rights which should be shared by all people worldwide; and

Whereas, historically some families, professionals and policy-makers have incorrectly assumed that people with severe disabilities are not capable of making choices in their own best interest; and

Whereas, in the past, decisions have often been made by professionals, families, policy-makers and others, based primarily on the assumption of what is in the best interest of the person with severe disabilities; and

Whereas programs and activities that relegate individuals with severe disabilities to a passive role do not encourage or allow a full range of choices that exist; and

Whereas, active attempts by people with severe disabilities to exercise choice or modify programs designed by professionals and families have often been interpreted as non-compliance, resulting in development of behavior programs to decrease the presumed "maladaptive" behavior;

Therefore be it resolved: The Association for Persons with Severe Handicaps affirms the right of persons with severe handicaps to freedom of choice in all types of settings; families and professionals should systematically work toward development of real opportunities and programs across all ages, for choice; and individuals with severe handicaps should be encouraged and supported to make choices through such activities as exposure, awareness, interaction and instructional opportunities, and research should be supported on successful methods that empower people with severe handicaps to make choices.

Subsidized Apartments to Open in Hibbing

Accessible Space, Inc. (ASI), A Twin Cities Area, nonprofit provider of housing and supportive care services for individuals with disabilities, will open of an 18-unit apartment building in Hibbing, Minnesota on June 1. . The building, called Winston Courts, will provide accessible, subsidized housing and 24-hour, personal attendant care services to individuals with mobility impairments.

Formed in 1978, ASI currently operates 12 sites in the Twin Cities Metropolitan Area. ASI serves over 120 individuals with mobility impairment, traumatic brain injuries and physical disabilities in residential and apartment settings. ASI also plans to open additional sites in Grand Rapids and Brainerd within the next two years. For further information or an application, contact Kathryn Lester, ASI associate director, at (612) 645-7271.

Parent Support Group to Begin

United Cerebral Palsy of Minnesota (UCP) in conjunction with Independence Crossroads, will forma a support group for parents with children with physical disabilities. The first session begins May 1 and will be an ongoing group. There is no fee. The group will meet from 7 to 9 p.m. at UCP, 1821 University Av. Suite 233-South, St. Paul. For further information, call (612) 646-7588.

RECREATION

Wilderness Adventures for 1989

Individuals who enjoy back-country travel may want to participate in one of Wilderness Inquiry's adventure trips. Since 1978, Wilderness Inquiry has provided affordable outdoor adventures open to everyone regardless of ability. The 1989 schedule of trips includes canoe trips to the Boundary Waters, Canada, Yellowstone Park, the Everglades, the Arctic, Rio Grande, and the St. Croix and Namekagan Rivers. Kayak tours of Lake Superior and the Queen Charlotte Islands are also offered. Costs range from $145 to $1,200. Trips do not include transportation from the

Twin Cities. Scholarships are available to people who qualify. For registration information, call Greg Lais, founder and executive director, at (612) 379-3858.

1989 Walk 'n' Roll

A wheelchair and walking rally, the Minnesota Walk 'n' Roll, will be held on Saturday, July 1, from noon to 5 p.m. Proceeds from pledges will assist individuals with disabilities to obtain computerized devices and other technological equipment. The Walk 'n' Roll will cover a 10-block distance in downtown Minneapolis beginning at the Juke Box Saturday Night located at 5th St. and Hennepin Av. T-shirts, hats, buttons, music and celebrities will all be a part of the event. Volunteers are needed to get sponsors and to assist at the rally. For further information, contact the United Handicapped Federation at 645-8922 (V/TDD) or 497-2800.

Fitness Video Available

A 60-minute fitness home video for older adults is now available. The video titled, "MORE ALIVE," is designed to increase flexibility, strength and endurance plus improve physical, mental and emotional health through gentle exercise. The video contains seven non-aerobic segments, each lasting eight minutes and it comes with a free fitness brochure. The exercises are led by Jo Murphy, host of the national television show, MORE ALIVE. She has worked in the field of gerontology for 20 years. The video is $24.95 plus $3 shipping and handling. A closed-captioned version for people with hearing impairments is also available. For more information or to order the video, call toll-free 1 (800) 873-3347, or write: Mature Adult Co., P.O. Box 98, Lafayette, CO 80026.

BOOKS

Strategies and Activity Ideas for Integrating Older Adults with Developmental Disabilities into Senior Centers, edited by Eunice Thruman.

The 109-page book is divided into two sections. Part I provides introductory and philosophical information. It describes types of integrated activities for older adults, what a senior center is and how to choose one and then how to integrate individuals into that center. The book uses the "Life Context" approach and describes what that is and how to use it. Part I is clearly laid out, written in easy-to-understand language and is practical and useful for the lay person.

Part II contains activity ideas. These include art, crafts, and hobbies; music and dance; sports and games; fitness and exercise; outdoors and nature; culinary activities; special events; educational information and other material. The life context approach is used with each activity and each is clearly presented. There is no charge for the publication. It is available from the Senior Center Integration Project, Kent Client Services, Grand Rapids, MI.

Supported Employment Conversion Planning Workbook, Maryland Supported Employment Project, Kennedy Institute, 1987. This workbook covers the tasks involved in converting all or part of a day program (e.g. work activity center, prevocational training program, or a sheltered workshop) into a supported employment program. Sixteen major planning areas are reviewed: agency readiness, feasibility study, parent and board approval, change management team, labor market survey, worker needs, staff development, organizational structure, facility use, staging strategy, job development, financing, residential coordination, transportation, contingency planning, and monitoring and quality control. The workbook helps the reader through the process, as well as to make adjustments in plans as factors change over time. The price for one copy is $20.00. Special price for an order in quantities may be requested. Contact: Maryland Supported Employment Project; Kennedy Institute; 2911 East Biddle Street; Baltimore, MD 21213. Tel. (301) 522-7500.

CONFERENCES/WORKSHOPS

June 2, 1989

The American Society on Aging will present a one-day seminar on **"The Real World of Case Management"**. The Long Term Care DECISIONS Resource Center at the University of Minnesota is a co-sponsor. The program is designed to explore the dual role of case mangagers: helping people with physical and cognitive disabilities to find their way in the system, and maintaining fair access and cost and quality controls. For more information, contact: American Society on Aging; 833 Market Street, Suite 512; San Francisco, CA 94102. Tel. (415) 543-2617.

Regional Workshops: "Screening for Alcohol and Drug Problems". Hazelden has developed an alcohol and drug screening tool for use with people with disabilities. As a result of this effort, three training workshops will be conducted with the following objectives: 1) to understand the signs and symptoms of chemical dependency; 2) to identify how chemical dependency is manifested in persons with physical disabilities; 3) to explore the obstacles to identification of this type of problem; and 4) to observe and practice the use of a screening tool. The dates and locations of the workshops are:

May 15, 1989St. Paul
May 17, 1989 Mankato
May 19, 1989Grand Rapids.

For further information, call Sue Johnson at (612) 462-7700, ext. 2519, or (612) 257-4010, ext. 2519.

INFORMATION EXCHANGE

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300 Centennial Office Building
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
612/296-4018

Member of
National Association of
Developmental Disabilities
Councils

VARIATIONS ON A THEME: 'SELF-DETERMINATION,' WHAT IS IT?

The following statements are excerpts from four keynote addresses which were presented at "The National Conference on Self-Determination by Persons with Disabilities," at the Crystal City Gateway Marriott Hotel, Crystal City, Virginia, January 9-10, 1989. The conference was sponsored by the U.S. Department of Education, Office of Special Education and Rehabilitation Services, in conjunction with the Research and Training Center on Community Living of the University of Minnesota and the Minnesota Governor's Planning Council on Developmental Disabilities.

* * * * *

Nancy Ward--"Self-Determination"

I became a self-advocate ten years ago. Being a self-advocate is very important to me because my self-advocacy skills taught me how to see myself as a person with confidence and determination. I did not (always) see myself as a person because of all the labels placed on me. People used to make fun of me all the time... I became a member of People First... (which) teaches people who have a disability how to speak out for themselves. It also teaches us our rights and responsibilities by showing us how to advocate for change in a positive way. People First was started by a group of people who were in an institution in 1975 in Oregon.

When I first became a self-advocate I didn't know how to direct my feelings in a positive way. I saw this commercial on Special Olympics. It made me mad because they were parading kids around the state showing how people should give money bacause of pity. So I yelled at the TV. My self-advocacy skills have taught me to write letters to tell people how I feel rather than to get mad about it.

Our group has done work in communities and on policy-making issues by testifying to our county commissioners on transportation, and we worked on getting a law passed in Nebraska dealing with labels like moron, idiot, imbecile, and retarded. We were able to get the labels out of Nebraska State Statutes. People First has helped us on the individual level as well as other levels.

* * * * *

Robert R. Williams--"Creating a New World of Opportunities: Expanding Choice and Self-Determination in the Lives of Americans with Severe Disabilities by 1992 and Beyond"

We already know that (self-determination) is just a ten dollar word for choice. That it is just another word for freedom... another word for describing a life filled with rising expectations, dignity, responsibility and opportunity. That it is just another word for having the chance to live the American Dream.

Why are we here? We are here to enable one another. We are here to empower one another. To empower one another to go home and empower others to become more self-determining in their own lives... Self-determination may start with the self, but, it cannot end there. It must pass along to others what we have learned for ourselves by making choices in life, taking calculated risks and living by their consequences.

You and I must take the time to listen to those whose choices and pleas to be heard would otherwise fall on the ears of individuals who can hear but refuse to really listen. We must stand beside those whose attempts to express themselves are frequently viewed by others as "aberrant," "offtask," "noncompliant," "inappropriate," "excessive," "challenging," "aggressive," "self-injurious," or "nonsensical." Indeed, (such behaviors are interpreted) as (being) anything but valid attempts to communicate real wants, needs, or desires to others.

We must stand with our brothers and sisters who are still in institutions and nursing homes throughout the land--all 176,000 plus of them. We must help them win their freedom. We must help them win back their human dignity and self-respect.

--Creating a New World of Opportunities for Americans with severe disabilities by 1992 (when we will be celebrating the 500th Anniversary of Columbus' discovery of the New World in 1492) must begin with putting an end to the discrimination we face today. For in a truly kinder, gentler, and more just America, equal opportunity must come to represent the rule of law rather than a mere exception to it. Passage of the Americans with Disabilities Act will go far toward enabling our country to achieve this vital national objective.

In creating a New World of Opportunities for Americans with severe disabilities, we must carry our message forward to President-elect Bush, the Congress, and the American people. We want our people free. We want them well-supported in the community where they always belonged in the first place. And we "want them out, out of institutions, out of nusing homes, out of variations on these themes." (Provencal, 1988).

* * * * *

Frank G. Bowe--"Self Determination at the Community Level"

To participate in the community, as someone seeking access to and changes in the programs and activities conducted there, someone with a disability does in fact have to have reached some accommodation with the disability. So it is very true that self-determination at the individual level almost always precedes that at the community level.

Growing up as the only person with deafness in Lewisburg, Pennsylvania, it simply never occurred to me that I could, or should, seek changes in the community.. .. I saw deafness as something that was "my problem," something unique to me, something in fact "wrong" with me.

It does take a leap of logic to comprehend that society has obligations to you, that the issues are ones of human and civil rights. It takes a further stretch of imagination to realize that people with other kinds of disabilities do in fact have much in common with you, that together you can make common cause. These things are not intuitive. But that leap, that stretch, must be taken before one becomes a community activist, before one expresses self-determination at the community level.

When I think about self-determination in the community ... (I think of) implementing and enforcing what is already supposed to be there, such as curb cuts, ramps, interpreters and readers, accessible voting booths.... It requires a willingness to stand up and be identified as someone who does in fact have a disability, who does have special needs. That, for many people, is not an easy thing to do.... It requires some sense of how the world works, of how public decisions get made.. . .It also requires an understanding of how to build bridges, to create coalitions, to bring together diverse groups to harness their energy and political power. Coalitions form around common interests. Self-determination may seem at conflict with community determination, but really it is part and parcel of the same thing. To the extent that I as an individual with a disability can make you see that you want what I want, to that extent I have increased by base, strengthened my hand, and expanded my options.

(My 15 years of experience) suggests that . . . you concentrate on how to, first, help people with disabilities to openly and unabashedly acknowledge their needs; second, teach people with disabilities how to influence the decision-making process in public and private organizations; and, third, guide people with disabilities in identifying allies with whom they can make common cause.

* * * * *

Gunnar Dybwad--"Self-Determination: Influencing Public Policy"

(Gunnar Dybwad started his presentation by illustrating how long it took for the independent living movement to become public policy. Starting with proposed legislation in 1957 and again in 1961, these services did not become a reality until the early 1970s.)

Why do I bring these old potatoes to your attention? Because very obviously there had not been enough manpower to influence the public policy in question.

Need I say more than to remind you of what happened to Ed Roberts in those very days in California, when he was downgraded as "not feasible" (to be habilitated) by those who should have served him? But Ed Roberts had gained for himself a different identity, not that of a dependent client, but of a citizen. His self-concept was clear--he did not allow the rehabilitation professionals to downgrade him, and with singular self-determination, he forged ahead, his severe physical impairment not withstanding, and eventually created our country's first center for independent living. In due course, he was appointed by Governor Jerry Brown to be the head of the State Rehabilitation Department that had cast him aside as "not feasible."

Gerben DaJong (1983), in exploring the reasons why persons with handicaps in general encounter as many obstacles if not outright rejection, saw the cause in the broad general scene. In an article on Physical Disability and Public Policy, he wrote:

> The ultimate and most pervasive of environmental barriers are the attitudinal ones, particularly the view that disabled people are helpless, pathetic victims, deserving charitable intervention. There is now more than enough experience to indicate that disabled people can, with appropriate environmental support, lead full and independent lives. Without the removal of attitudinal barriers, the disability legislation of the past decade will not realize its full promise.

To achieve such a basic change in attitude will take precisely what our session today is all about. It will take the effective, long-range influencing of public policy on all levels of governmnet, legislative, executive, and judicial--and the action has to come from the persons with disabilities themselves.

Throughout my long friendship with Robert Perske, he has time and again redirected my thinking into new and innovative channels, and he does so with formulations which at first sound so very simple--until you begin to fully understand their significance. Let me then quote from his concluding words in Circles of Friends:

> As people take to each other, persons with disabilities have been able to contribute their own unique richness to their friends and to the surrounding neighborhoods as well. Therefore, I believe that friendships with people who have disabilities can provide an explosion of fresh values and directions which this confused, misdirected world needs now as never before.

STUDY SHOWS SUPPLEMENTAL SECURITY INCOME PROGRAM UNDER-UTILIZED

As reported by Dennis Lien, staff writer for the St. Paul Pioneer Press Dispatch (April 18, 1989), "Three of five Minnesotans eligible for Supplemental Security Income (SSI) do not receive it, primarily because they are unaware it exists or that they qualify." This finding was revealed in a recent survey conducted by the Villers Foundation of Washington, D.C.

Surveyors of the Villars study, entitled SSI Aware: Why the Elderly Poor Don't Get the Help They Were Promised, said public information by the Social Security Administration is inadequate, and that this has contributed to a steady decline in the number of Americans taking advantage of the program, which was approved by Congress in 1972. It was recommended that more intense and systematic publicity efforts be made by the administration, local Social Security offices, and community organizations. Also, government must make it easier for people to apply, the writers of the report stressed.

The survey revealed that 51 percent of the 4 million people who would be elibible nationally took advantage of the SSI program. In Minnesota, only 39 percent of 33,900 eligible were receiving SSI. Participation rates for the 18 states surveyed showed a low of 27 percent in Indiana and a high of 64 percent in Washington.

Supplemental Security Income serves as a safety net for eligible people with low incomes and over age 65 and people with disabilities or blindness. The program offers a guaranteed minimum income of $85 a week for one person and $128 for a couple. To be eligible, single people must have liquid assets of less than $2,000, and couples must have less than $3,000. In addition to receiving the income, recipients automatically are eligible for food stamps and Medicaid.

One copy of the survey report is free, and each additional copy costs $5.00. Contact: Villers Foundation; 1334 "G" Street, Suite 300; Washington, DC 20005. Tel. (202) 628-3030.

For more information about programs administered by the Social Security Administration, there is a helpful resource available: A Summary Guide to Social Security and Supplemental Security Income: Work Incentives for the Disabled and Blind, SSA Pub. No. 64-030, ICN 436900, July 1987. These may be acquired at: Social Security Administration Regional Commissioner, SSA; ATTN: Disability Program Branch; 10th Floor; 105 West Adams Street; Chicago, IL 60603.

INDIVIDUAL HABILITATION PLAN REVIEW FORM AND MANUAL PUBLISHED

The Minnesota Disability Law Center of the Legal Aid Society of Minneapolis recently released two documents, "Individual Habilitation Plan (IHP) Review (Form)" and "Reviewer's Manual." These products were developed with funds provided by a grant awarded by the Administration on Developmental Disabilities of the Office of Human Development Services of the United States Department of Health and Human Services.

The IHP Review Form was developed to evaluate the quality of services provided to adults with severe disabilities who are receiving services in community settings. The review process serves as a set of standards for providing services to persons with developmental disabilities which reflects best practices. Scope of the review includes: environment; mealtime observations; health and safety; overall program issues (including quality indicators for IHP objectives and intervention procedures, goals and objectives, and evaluation checklist); independent living skills; community integration; vocational skills; communication skills; behavioral special needs; physical and sensory special needs; and case management.

The IHP review process can be used to affect change in the lives of individuals as well as in the broad array of community services as they influence the quality of life for many people with developmental disabilities.

In addition to the two IHP publications, a report about the development and implementation of the IHP review project is available. Contact: Minnesota Disability Law Center; 222 Grain Exchange Building; 323 Fourth Avenue, South; Minneapolis, MN 55415. Tel. (612) 332-1441, or (800) 292-4150, toll free from within Minnesota.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resourc materials. **The following materials may be borrowed from the State Office only, located at the address on th ront sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.**

LENDING LIBRARY SELECTIONS

Aging . . . A Shared Experience, (Videotape, VCR, 1/2 inch, 20 minutes), and Discussion Guide. This videotape was conceived and directed by Matthew P. Janicki, and was funded by the Joseph P. Kennedy, Jr. Foundation. The production focuses on community integration of older Americans with mental retardation or other developmental disabilities. It tells the story of several such older Americans as they use senior services. Interviews with national figures include Dr. T. Fanklin Williams, Director of the National Institute on Aging, Congressman Claude Pepper, and Eunice Kennedy Shriver. This videotape is desined to be used for community education, staff training, and program development by workers in a variety of human service settings. Accompanying the tape is a Discussion Guide, which lists other resources for learning more about people with disabilities who are aging.

The following tapes were produced by the Governor's Planning Council on Developmental Disabilities:

An Interview with Lou Brown, 47 minutes, (April 1987). Lou Brown, Professor at the University of Wisconsin in Madison, talks about his research in the area of supported employment for persons with severe disabilities.

An Interview with Gunnar and Rosemary Dybwad, 47 minutes, (February 1987). The Dybwads speak from historical and international perspectives about the advancements made by persons with disabilities and the many challenges remaining in order to participate more fully in society.

An Interview with Betty Hubbard, (May 1987). Through Hubbard's experiences as a leader in the field of developmental disabilities, the viewer gains an appreciation of what went on behind the scenes in the development of landmark legislation and community services in Minnesota.

Metropolitan Council DD Program
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300 CENTENNIAL BLDG
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SPECIAL OLYMPICS: A REVIEW AND CRITICAL ANALYSIS

Editor's Note: When Special Olympics began in 1968, there were virtually no other programs that addressed the physical education/fitness needs of people with developmental disabilities. Since 1975, with the passage of Public Law 94-142 and the recent developments in community services, Special Olympics has met with criticism over its segregated programming as well as other issues. Jack J. Hourcade, Department of Teacher Education, Boise State University, Boise, Idaho wrote an article with the above title in the Therapeutic Recreation Journal. Below is a synopsis of that article. The conclusions stated below are not those of the editor or the author. They are the results of research by other authors. References to the other research has been omitted due to space limitations. For a copy of the complete article including references write to: DD Program, Metropolitan Council, Mears Park Centre, 230 E. Fifth St., St. Paul, MN 55101.

During the 20 years since its inception the Special Olympics program has expanded tremendously, with well over one million athletes participating worldwide, and over one half million volunteers conducting activities in 16 sports. This paper is intended to identify perceived limitations of the Special Olympics program, and to outline possible modification of and alternatives to the present system.

Limitations

Segregation and Normalization

The principle of normalization has become an inherent guiding philosophy in program development for individuals with developmental disabilities.Special O by its very nature a "special" or segregated activity, has been frequently criticized on the basis of its lack of adherence to normalization philosophy. Motor skills is the domain of greatest congruence between group characteristics of individuals with and without mental retardation (yet) situations in which nonretarded individuals are assembled to observe only participants with mental retardation may only highlight the deviant characteristics of the participants. Segregation of the program in its organized competitions is further exacerbated by the typical tendency of delegations to socialize only within their specific groups. Staying together as a closed group, living together, and eating together in temporarily vacated university dorms and cafeterias...further limit...opportunities...to interact with nonretarded individuals.

Nonfunctional Skills

Of great concern to some is the lack of practical utility of skills taught. The skills learned are highly specific and are of limited use in subsequent leisure environments. S. O. emphasizes primarily track and field related skill; activities that are typically isolated and nonfunctional. One author suggested that spectators at S.O. events are actually acquiring a leisure skill which is more normalized, and more likely to generalize to the future, than are the participants themselves.

Inefficient Utilization of Instructional Time

Many participants in Special Olympics have significant skill deficits in such functional areas as communication, self-care, socialization, and leisure and recreation. Instruction time spent on such isolated skills as the 50-yard dash is time not spent on more crucial functional skills with greater practical value. Unless S.O. training involves the acquisition of a set of behaviors and skills likely to be useful now or in the future to the participant, it represents a nonproductive use of that individual's learning time.

Child-like Atmosphere

While S. O. includes adolescent and adult as well as child participants, much of its atmosphere is specifically oriented towards children. "Huggers" at the finish line, the presence of circus festivities and clowns, the widespread utilization of bright yellow "school" buses, the tendency to refer to all participants as "kids" and the encouragement of wearing medals for months after the events all serve to strengthen the public perception of adults with mental retardation as functionally child-like. In addition a significant proportion of the supervision typically provided to participant is overprotective and age-inappropriate.

Labeling and Stigmatization

The term "Special Olympics" has become inextricably linked in the public mind with a stereotyped perception of mental retardation and other disabilities. Individuals do not like, and will actively seek to avoid being labeled "mentally retarded." (As a result) significant numbers of children, especially adolescents, withdraw from participation for this very reason.

Patronization of Participants

While Special Olympics has been effective in eliciting publicity, an unfortunate amount of that publicity is condescending and patronizing towards the participant. The emphasis in much of the public advertising by the corporate sponsors of S. O. is on participants' success in the isolated and segregated athletic program, not on individuals with mental retardation achieving success in competitive vocational setting, community recreation organizations and independent living.

In news articles participants were described as "enchanted creatures" and "angels unaware." The S.O. organization perpetuates this patronization by reprinting and including that article in subsequent...information packets.

Evocation of Sympathy, Pity and Charity

Much of the publicity surrounding S. O. remains at least potentially stigmatizing. (Authors) note that when appeals are made...for funds or volunteers, those requests are designed to elicit sympathy for the participants, rather than respect.

Competitive Nature

(While) the philosophical goals emphasize the values inherent in participation, S. O. remains primarily a competitive program, rather than one focusing on individual development over long term.

Lack of Empirically Verifiable Benefits

The S. O. program outlines such philosophical goals as the enhancement of the social and psychological as well as the physical development of participants. Even supporters of S. O., however, acknowledge that such claims may be overstated. S. O. sponsored a three-year study to investigate the potential benefits of participation. The study was methodologically flawed with biased subject selection procedures. Even with this bias, the findings failed to identify objective measures supporting most purported benefits of the program.

Possible benefits

Despite whatever limitations S. O. may possess today, historically a number of positive aspects of the program have been proposed. These benefits include the (a) additional attention and social opportunities the participants receive in a warm and supportive atmosphere; (b) the publicity mental retardation receives from the competitions (estimates of 15,000 newspaper stories and hundreds of local TV and radio stories, plus coverage in such magazines as *Time and* Sports Illustrated); and (C) potential gains in physical fitness and recreation skills experienced by participants.

Alternatives and Conclusions

There is little question that Special Olympics originated as an effective response to the significant recreational and athletic program deficits in the schools and communities encountered by persons with mental retardation in the 1960s. (However), given today's philosophical emphasis on integrating individuals with mental retardation with their nonhandicapped peers, as an alternative to Special Olympics, schools and community recreation programs should develop specific guidelines and procedures designed to achieve maximal levels of integration in existing programs.

This is especially crucial given the intent of federal legislation such as Public Law 94-142, which requires that physical education programming be provided to children with handicaps in the least restrictive environment, and Section 504 of the Rehabilitation Act of 1973, which clearly prohibits discrimination against individuals with disabilities in programs receiving federal funds.

With the recent dramatic increase in such noncompetitive recreation events as "fun runs," one obvious solution is to provide (people) with handicaps the opportunity to participate in these and similar community recreation programs. Other age-appropriate events might include church and community center dances, league athletic events, 4-H groups (for children) and community swimming classes.

Within the Special Olympics format itself, a number of possible modification options exist. One alternative is to restrict participation to only those individuals who are unable to participate in and profit from integrated athletic programs in a successful and meaningful fashion, removing specific IQ levels as selection criteria.

Another alternative is to integrate Special Olympics itself. One author noted the drawbacks of the stigmatizing term "special, and suggested that the program be renamed the Kennedy Olympics, a move which would also serve to recognize the significant founding roles of both the Kennedy family and the Kennedy Foundation. Under such an aegis, nonhandicapped individuals also would be able to participate.

Since its inception in the 1960s, Special Olympics has resulted in many historically significant benefits for its participant, volunteers and for society at large. It has helped to make mental retardation more clearly understood by society at large, and has changed the lives of thousands involved for the better. As times have changed, however, both for society in general and for individuals with mental retardation in particular, programs must change and evolve as well. Special Olympics began as a response to the perceived needs of the times. It may now be time for Special Olympics to effectively respond once again to the contemporary needs of its constituency.

Success Stories Sought

Do you know someone who has overcome barriers to obtain employment, attend a regular class in school, to live on their own with support, or to participate in recreational activities with nonhandicapped people? Please share your story. It doesn't have to be a monumental success. The Adult Services Committee of the Minnesota Association for Persons with Severe Handicaps is seeking success stories. The Committee wants to publish the stories in a booklet to share with people throughout Minnesota. It hopes the stories will inspire and support others in their efforts to realize their dreams and hopes of greater independence and control over their own lives.

You don't need to write up the story. The Committee members will interview you and obtain the necessary permissions to print the story. If you have a story to share, please call the editor of this newsletter, Kay Zwernik, at (612) 291 6364 or write of your interest in this project to the DD Program, Metropolitan Council, Mears Park Centre, 230 E. Fifth St., St. Paul, MN 55101.

FOR YOUR INFORMATION

Council Publication Receives Award

The recently published booklet, "It's Never Too Early, It's Never Too Late," received an award from the Minnesota Association of Government Communicators. The Award of Excellence, their highest award, was given to Kay Zwernik, author of the book. The award is for the best technical publication over 20 pages. The booklet is about Personal Futures Planning for people with developmental disabilities. It was developed under a grant from the Governor's Planning Council on Developmental Disabilities and published by the Metropolitan Council. Cathleen Casey was the graphic artist.

To order a free copy of the booklet write to the Data Center, Metropolitan Council, Mears Park Centre, 230 E. Fifth St., St. Paul, MN 55101.

WORKSHOPS/CONFERENCES

June 16-17, 1989

"Nurturing Learning in Infants and Young Children" will be presented by Magda Gerber, nationally recognized infant specialist, educator and consultant. Friday's session will be at the Jerome Hill Theater, First Trust Center, 180 E. 5th St., St. Paul from 11:30 a.m. to 1 p.m. The cost is $5. The Saturday session will run from 10 a.m. to 4 p.m. at the St. Paul Technical Institute, 235 Marshall in St. Paul. The cost is $10. Call the Working Parent Resource Center at 293-5330 for further information.

June 20, 1989

"An overview of Developmental Disabilities for People Who Serve People with Developmental Disabilities in the Community" will be held twice, one from 9:30 to 11 a.m. and the second from 1:30 to 3:30 p.m. at the Comfort Inn, 2715 Long Lake Road in Roseville. Sponsored by Thomas Allen, Inc., the workshop will cover a review of the definition of developmental disabilities, a history of services, causes, learning characteristics, the principle of normalization, the least restrictive environment and partial participation. The cost is $15. For further information or to register, call Ellie Field at 450-1802.

June 21-22, 1989

"Improving the Quality of Life in Home and Community...Instructional Strategies for Persons with Mental Retardation" is the title for a conference sponsored by The Research and Training Center on Community Living at the University of Minnesota, The Association for Residential Resources in Minnesota and the Association for Retarded Citizens-MN. The conference will focus on practical approaches to teaching community-referenced recreation, leisure, communication and domestic skills. Nationally respected experts representing the leading edge of quality service development for adults with mental retardation will address:

- Implementing practical intervention strategies to teach recreation, leisure, communication and domestic/household skills.
- Maximizing client participation in community activities.
- Establishing positive approaches to the management of challenging behaviors.
- Serving clients who require special health care in community environments.

The conference will be held at the Roseville Holiday Inn, 2450 Cleveland Av. N. in Roseville. Registration is $50. Make checks payable to the University of Minnesota and send to: Quality of Life Conference, Research and Training Center, 110 Pattee Hall, U of M, 150 Pillsbury Dr. SE, Minneapolis, MN 55455. For further information, call (612) 625-3396.

June 21-23, 1989

"Shine On, Minnesota!" is the title of the Summer Training Conference sponsored by the Minnesota DAC Association, the Minnesota Association of Rehabilitation Facilities and the Staples Technical Institute. It will be held at Madden's Resort in Brainerd, MN. The three-day conference will include two keynote addresses and 33 workshop presented by representatives of government, universities, service providers, private consultants, advocates and other qualified experts. The conference is $110 and does not include meals and lodging. For further information, call MARF at (612) 646-0900 or MnDACA at (612) 647-9200.

October 19-20, 1989

"Integrated Education: Realizing the Vision" will b a national conference designed to provide information on strategies and program models which have been effective in designing, delivering, and evaluating quality integrated education programs for learners with severe disabilities. A second objective is to provide an opportunity for participants to network with others who are working to build integrated school communities, exchange ideas, support one another, and share successes and visions of children learning together. Marsha Forest, well known advocate of integrated education for all children, who is Director of Education at Frontier College and Director of the Centre for Integrated Education will be the keynote speaker. Other speakers include Tom Gilhool, George Flynn, Barbara Buswell, Jeffrey Strully, Susan Stainback, William Stainback, Robi Kronberg, Terri Rogers-Connolly, Richard Schattman, Doug Bilken, Sharon Freagon, Bill Peters, Alison Ford, Luanna Meyer, Jacqueline Thousand, Linda Kjerland, Diane Gerads-Schmidt, Judy Neis and Jean Mendenhall. The conference will be held at the Scanticon-Minneapolis Conference Center in Plymouth. The fee is $200 and for parents, students and paraprofessionals $100. For additional information regarding the program, contact Terri Vandercook or Jennifer York at (612) 624-4848. For additional information on registration, contact Denise Callies at (612) 625-3061.

RECREATION

Camp Courage

Children and adults with physical disabilities and communication disorders may register now for Courage Center's summer camps located near Maple Lake or on Lake George in northern Minnesota. Both camps offer accessible natural environments. Camping sessions run from one to three weeks between June 5 and August 25 for campers aged seven to seniors. For further information or an application, contact the Camping Dept., Courage Center, 3915 Golden Valley Road, Golden Valley, MN 55422 or (612) 520-0540.

Camp Sunshine Connection

The Sunshine connection is a program of day camping that is intended for children and adults who have autism and who do not have other suitable community activities during the month of August. The camp operates for 19 days from Aug. 1-25 at the Armatage Neighborhood Center, 57th and Russell Av. S., in Mpls. The fee is $250 including transportation. There are both morning and afternoon sessions. For information, call 560-5330.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
June 1989

Developmental Disabilities Program
300 Centennial Office Bldg.
658 Cedar St.
St. Paul, MInnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*

Member of
National Association of
Councils

FROM BEING 'IN' THE COMMUNITY TO BEING 'PART OF' THE COMMUNITY: NATIONAL LEADERS PONDER ISSUES

On November 21-22, 1988, a National Leadership Institute on Community Integration for People with Developmental Disabilities was held in Washington, D.C. The Institute was designed to identify the current state of knowledge and practice in community integration and to recommend directions for future efforts.

The Research and Training Center on Community Integration, Syracuse University, convened this meeting in cooperation with the National Institute on Disability and Rehabilitation Research within the Office of Special Education and Rehabilitative Services. Participants included representatives of major university research and training centers, parents, people with disabilities, policy specialists, and representatives of major national developmental disability organizations, as well as federal officials.

Cory and Ralph Moore, parents, captured the essence of this two-day session, saying: "We are at the beginning of a new venture into the community for a person with multiple handicaps and we know it can work. There are, however, some important quality-of-life learnings already emerging. For professionals: Bureaucracies are run by well meaning people who often are caught in rules, procedures, and ways of doing things that other well-intentioned people have put in place. When rules stand in the way of full citizenship, they can be adapted, modified, or changed. Think always with creativity and innovation and, above all, start by focusing on the individual rather than the system. . . . For families: Become aware of your child's preferences. Plan for the future. Trust your vision. Help agencies design individual support systems. Band together with other families and create your own community network. Always keep your son or daughter the focus of brainstorming. Communities are filled with people who will connect, if the opportunities are offered. Our children can be truly valued, important, participating community members."

The Institute was organized around four work groups: community living, families, education, and employment. Four themes emerged that cut across these areas:

- It is a reality in a growing number of communities that people with developmental disabilities can live, work, and go to school in typical settings. This policy direction is supported by a steadily growing body of research and practical experience.

- As a future priority, attention must be directed toward helping people with developmental disabilities to achieve full integration and participation in the community--not merely to help them to be **in** the community, but to be **part** of the community as well.

- While "islands of excellence" can be found across the country, programs in most states and communities fall far short of the standards set by the best programs.

- An insufficient policy and economic base exists to support community integration efforts. Federal and state policies and funding mechanisms continue to support segregation rather than integration for people with developmental disabilities, e.g, Medicaid. Public policy lags significantly behind the "state-of-the-art" and, in many cases, threatens to circumscribe further progress.

There remains much more to do and to learn.

Community Living

Many questions emerged regarding what it means to be a part of a community: How do we promote social relationships between people with developmental disabilities and other community members? How do we design supports around people rather than fitting people into programs? How can we enhance quality of life? How do we maximize freedom of choice and self-expression? How can we balance independence with interdependence? While new challenges emerge, the fact remains that 93,000 people with developmental disabilities remain in public institutions and over 80,000 live at private institutions and nursing homes.

What is known about community living:

- All people with developmental disabilities, including those with severe developmental, behavioral, and health impairments, can live successfully in the community if appropriately supported.

- Institutions and other large, segregated living arrangements are unacceptable places for people with developmental disabilities to live. Any resources available in institutional settings can be made available in community settings.

- Evidence and experience indicate that life in the community is better than life in institutions in terms of relationships, family contact, individual development, and leisure, recreational, and spiritual resources.

- Both children and adults with developmental disabilities benefit from stable relationships with other people, including family members, foster and adoptive families, and nondisabled community members.

- People with developmental disabilities can and do make positive contributions to the life of the community.

Some of the recommendations made by the work group on community living included:

- Future research and funding should be directed toward the study of social relationships, integration, and networks. There is a need to study the meaning and nature of community integration for members of minority groups, urban populations, elderly people, and people with the most severe disabilities.

- Technical assistance and training should be directed toward: 1) policymakers (e.g. study tours, and policy institutes for policy officials); and 2) families, people with developmental disabilities, and service providers on critical issues (e.g. citizen monitoring, self-advocacy, generic resources, and social relationships).

- Disseminate information using multi-media to diverse audiences regarding policy implications, research findings, and successful examples of community integration.

Families

As stated by Ann P. Turnbull and H.R. Turnbull, Beach Center on Families and Disability, University of Kansas, "Family decision-making about needs and priorities is obviously strongly influenced by the nature of expectations. Many families are confused about what to expect with respect to integration (they are still experiencing 'deinstitutionalization jet lag'), and they are still 'carrying baggage' from lowered expectations generated at various points of their lives and by various professionals, policies, and public attitudes. A concerted effort at raising family expectations can substantially increase the nature and extent of integration. . ."

Public policy and services for families of people with developmental disabilities must reflect revised assumptions about: **perceptions of disability** (from viewing the person with a disability as a burden to seeing the person as a contributing member of the family and community); **family member roles** (reflecting individual family members' preferences and choices); **family-person-professional partnerships** (from viewing families and people with disabilities as passive recipients of services to respecting them as equal partners); **professional services and informal supports** (toward striking a balance between formal programs and informal supports); and **family support services** (toward helping families "dream" or form a vision of a desirable future for their son or daughter.

What is known about families:

- Society and its reactions to disabilities impose stresses and pressures on families.

- Families know best about what they need to support a member with a disability.

- Family support services in practically all states and communities are inadequate and in many cases inappropriate for most families.

The work group on families made some of the following recommendations:

- Future research and funding should be directed toward the study of family perceptions, family members' roles, person-family-professional partnerships, professional services and informal supports, as well as how different kinds of support services impact on families, including families from minority and other traditionally underrepresented groups.

- Training must be provided regarding changing assumptions. Technical assistance should be provided to states on implementing promising practices for supporting families.

- **Technical assistance provided to policymakers should include training from family members and people with disabilities.**

- Prepare information for diverse audiences, give practical information without jargon to families, and present positive images of people with disabilities and families to the media and policy makers.

Education

Douglas Biklen, Syracuse University, observed, "Inconsistency . . . is a national phenomenon. Where a student lives has a lot to do with whether he or she attends a regular school."

"Supported Education" provides a direction for efforts to enhance the quality of education for students with disabilities and indeed for all students. Supported education means bringing the supportive services needed for students with developmental disabilities into regular classrooms, which entails: schools as inclusive communities; all students attending local schools; a team approach for staffing allowing flexibility and creativity in meeting students' individual needs; special educators as a resource to regular educators; fiscal incentives to integrate students with disabilities; and a philosophical commitment to accepting students with developmental disabilities as capable learners who can achieve, and who belong with their typical peers.

What is known about education for children with developmental disabilities:

- All students with disabilities, including those with severe disabilities, can attend the same public schools they would attend if not disabled, and all can participate in regular school programs at the preschool, primary, and secondary levels.
- The qualities and practices necessary to make integration work for students with developmental disabilities are the same qualities and practices that characterize effective schools for all children.
- Integration of students with disabilities positively affects the school environment for all students and staff.

Recommendations from the work group on education included:

- Research and funding must be directed toward: qualitative case studies; student outcomes of integration; administrative practices such as transportation, funding, and policy implementation; fiscal practices; impact on families and nondisabled students.
- Training and technical assistance regarding supported education should be directed toward: regular education policymakers, officials, and leaders; parents; "master teacher" programs for experienced teachers; and preservice and inservice training for regular educators, administrators, related services personnel, and hearing officers.
- Information needs to be provided using common language (with words that are nonstigmatizing) for policymakers, educators, and families. Successful and promising practices need to be disseminated widely, positive outcomes need to be documented, and such information must be accessible to members of minority groups and other traditionally underserved groups.

Employment

People with all types of disabilities can work and are working. Many people who were considered unemployable a few years ago now hold paying jobs. Research and practice have shown that supported employment is feasible, desirable, and cost-effective.

"The idea is eloquently simple:" said Paul Wehman, Virginia Commonwealth University, "place persons who have never worked competitively before into real work settings, provide training at the job site, and then provide long-term maintenance in the form of job coaches, attendants, coworkers, volunteers, or whatever type of support service seems to work."

Yet, despite the widespread success of supported employment programs, major policy and fiscal barriers stand in the way of expansion: Medicaid, inadequate funding from vocational rehabilitation agencies, work disincentives imposed by the administration of Social Security programs, inadequate incentives for industry, and a lack of interagency collaboration.

What is known about work:

- The vast majority of people with disabilities are unemployed, with unemployment the highest among women, members of minority groups, and people with severe disabilities. Among people with disabilities who do work, severe underemployment exists in terms of hours worked.
- Schools seldom provide appropriate vocational training to prepare students with developmental disabilities to be employed.
- In virtually every state and community in the country, a crisis exists in the capacity of service providers to provide post-school services to adults with developmental disabilities.

Recommendations made by the work group on employment included:

- Research and funding should be directed toward: policy initiatives and service approaches, e.g. administrative and programmatic practices for supported work, including approaches for the conversion of segregated services to supported work; social support and community participation; employment statistics and labor market trends; and the economics of supported employment.

- In addition to providing training and technical assistance to current providers of supported employment, others should be included, such as professionals in rehabilitation, administrators, educators, employers, and parents. People with developmental disabilities and family members should be involved in planning and providing training and technical assistance.

- Increase public awareness, including the media and employers; disseminate research findings; and develop information for policymakers on the national and state level.

Conclusion

Several concepts were stressed at the Leadership Institute. New ideas will help set a direction for the future:

dreams for the future
complete school
interdependence
respect
reciprocity
unobtrusive support
community building
future planning
supported education
positive contributions
full citizenship
partnership
informal support
equity
empowerment
diversity
regeneration
autonomy
choice
friendship

To obtain a free copy of From Being in the Community to Being Part of the Community: Summary of the Proceedings and Recommendations of a Leadership Institute on Community Integration for People with Developmental Disabilities, contact: 1) Rachael Zubal, Center on Human Policy, School of Education, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-2340 (Tel. 315-442-3851); or,
2) Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155 (Tel. 612-296-4018, or 612-296-9962 [TDD]).

Copies of detailed reports may be purchased through the Center on Human Policy (see above): Complete Proceedings ($15.12); Community Living ($6.32); Families ($2.40); Education ($1.68); Employment ($2.88).

PUBLICATIONS/RESOURCES

What Are We Learning About Circles of Support? A Collection of Tools, Ideas, and Reflections on Building and Facilitating Circles of Support, B. Mount, P. Beeman, and G. Ducharme, Communitas, Inc., 1988. The purpose of this monograph is to help people with disabilities and their family members to clarify goals, identify obstacles and opportunities, and to bring together friends and community members to help overcome obstacles and to find new opportunities. A circle of support is described as a group of people who agree to meet on a regular basis to help the person with a disability accomplish certain personal visions or goals. Experiences of 25 circles of support in Connecticut are portrayed. The authors state, "People with disabilities and their families acquire more power to influence the direction of their lives through establishing new connections in the community, by changing the systems they depend on for support, and by overcoming personal barriers with the support of the people around them who are committed to the vision." For information on how to purchase, contact: Communitas, Inc.; 73 Indian Drive; Manchester, CT 06040.

What Are We Learning About Bridge-Building? A Summary of a Dialogue Between People Seeking to Build Community for People with Disabilities, B. Mount, P. Beeman, G. Ducharme, Communitas, Inc., 1988. Bridge-builders as referred to in this monograph are those who initiate, support, and maintain new relationships so that persons with disabilities can be successful in their efforts to become integrated in their communities. According to the authors, "Bridge-builders seek to break old patterns by: 1) recognizing and encouraging the capacities and gifts of people with disabilities;
2) building community by establishing and strengthening relationships for people with disabilities; 3) rearranging human service supports so people can live in their own homes, work, and contribute in community life; 4) taking direction from people with disabilities and the people who know them well; 5) believing in the capacity of natural communities to accept and include people with disabilities, and by believing that when community is responsive to one person, it becomes stronger for all of us." The stories shared in this publication illustrate both the diversity of approaches as well as the assumptions and practices that community bridge-builders share. For purchase information, contact: Communitas, Inc.; 73 Indian Drive; Manchester, CT 06040.

"1989 Community Transportation Resource Guide," a special issue of Community Transportation Reporter: The Magazine of the Rural and Specialized Transit Industry, (January 1989), Vol. 7, No. 1. This special issue lists national, regional, and state information resources for community transportation. Section I provides information on all the major federal funding resources, such as Urban Mass Transportation Administration (UMTA), the U.S. Department of Health and Human Services, and the U.S. Department of Labor. Section II lists key congressional committees and subcommittees that are of interest to the community transportation industry. Section III provides a comprehensive listing of resources and clearinghouses, along with detailed data on national associations and industry periodicals. Section IV presents a roster of program contacts at the federal and regional levels. Section V provides a comprehensive state-by-state profile of UMTA's funding allocations as well as important transit-related contacts. Price for this special issue is $7.50. For purchase and subscription information, contact: Community Transportation Reporter; 725 15th Street, NW, Suite 900; Washington, DC 20005. Tel. (800) 527-8279.

MINNESOTA ALLIANCE SCHEDULES TRAINING SESSIONS

The Minnesota Alliance for Training and Technical Assistance has scheduled the follow training events:

TOPIC	LOCATION/DATE
Administrative Issues in Supported Employment	St. Paul, June 9, 1989
Economic Development	Brainerd, June 21-23, 1989
Determining Fair and Equitable Wages for Hourly Employees	Rochester, July 13-14, 1989
Creative Options: Working with Persons with Severe Disabilities	Minneapolis, Sept. 14-15, 1989
Employment Training Specialist Symposium	Duluth, Sept. 19-22, 1989
A Business Orientation to Job Development	Willmar, October 5-6, 1989

For more information, call (612) 624-0232, or (612) 626-7220.

Celebrate
MINNESOTA
1990

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

LENDING LIBRARY SELECTIONS

It's Never Too Early, It's Never Too Late, Videotape (VHS, 1/2 inch, including a closed captioned version for persons with hearing impairments) and It's Never too Early, It's Never Too Late: A Booklet About Personal Futures Planning, by Beth Mount and Kay Zwernik, 1988. This videotape and guidebook were developed by the Developmental Disabilities Program of the Metropolitan Council, under a grant from the Minnesota Governor's Planning Council on Developmental Disabilities. Personal Futures Planning is a process of looking at the relationships, experiences, gifts, and capacities that an individual has in order to develop a vision for the future. Such a vision summarizes the opportunities and capacities to work for the person in their connections with family, friends, and staff in the community and in the resources and opportunities in the service system. Personal Futures Planning can complement the Individual Habilitation Planning process, and can aid in ongoing problem-solving for the individual with developmental disabilities.

The Case Management Team: Building Community Connections, (Videotape, audiotape, and booklet), by Toni Lippert, Developmental Disabilities Program of the Metropolitan Council, 1987. This set of resources was produced under a grant from the Minnesota Governor's Planning Council on Developmental Disabilities. These aids help persons with developmental disabilities, family members, county case managers, and other service providers understand more about the process of case management. The videotape gives an overview of how quality case management can achieve genuine community integration. The audiotape is a series of interviews by three professional people who discuss with a parent what case management means and how families can be active participants in major decisions about services. The booklet is written from the family viewpoint, containing comprehensive information and resources that reinforce methods for building community connections for persons with developmental disabilities. A variety of checklists help readers determine whether services are of high quality and are promoting integration outcomes.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

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St. Paul, MN 55101

(TIME-DATED MATERIAL)

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INFORMATION EXCHANGE

Published monthly by the Developmental Disabilities Program of the Metropolitan Council
Editor: Kay Zwernik

Metropolitan Council
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Vol. 14, No. 7
July 1989

1989 AGENDA ACCOMPLISHMENT

On July 1 Linda began a new employment position at the University of Minnesota Minneapolis campus. Her role will be Assistant Counselor/Advocate in the Office of Students with Disabilities. In that position she will be able to provide information on resources and contribute advice to others based on her experience and extensive knowledge of the service system. With B.A. and M.S. degrees from St. Cloud State University in the counseling psychology and several years experience with advocacy and information and referral, Linda is well qualified for her new position.

Linda is a beautiful, intelligent, outgoing, caring and conversant young woman who enjoys life. Her life includes lots of friends and social activities, close family and extended-family relationships, travel to exotic places and living in an apartment with two roommates. Linda's life sounds just about like anyone else's who is a bright, attractive young single person--except that Linda has spinal muscular atrophy, a recessive gene disorder which is a form of muscular dystrophy. It is something she has lived with her entire life, but Linda hasn't let it interfere with getting what she wants out of life.

Linda was born in a small community in southwestern Minnesota and grew up on the family farm. As a result of her disability, she was not able to attend public school. The several-story building did not have an elevator and the bus had no wheelchair lift. Public Law 94-142 was in effect but her parents were not informed of her rights and the school chose to ignore the law that requires an appropriate public education for her. Thus, Linda went through the eighth grade with a home school teacher two hours twice a week.

When she finally was able to attend high school in town, her father drove her both ways every day for four years. On her first day of school, the principal called an assembly and introduced Linda as the new student. Then he said, "Linda is going to need some help getting from class to class. She needs some volunteers--You, You and You," pointing to three strong boys in the front row. Actually they enjoyed the job because they were able to come to class late and leave early to push Linda's chair or carry her up and down stairs.

Some of the students in her class knew her from the parties and special programs she had attended at school. Linda, however, did not realize until she attended school just what she had missed in forming friendships. The isolation of the farm became apparent. It did not, however, mean she had no peer contacts for she has a large extended family throughout the area where her family lives, and they held lots of get-togethers.

During high school Linda sought to be a regular student. On Fridays she regularly attended basketball games and went with the team to the state tournament.

She was the only girl with 13 boys in an Ag class and in Future Farmers of America (FFA), where she was also an officer. She went to parties, was in speech club, took the class trip to Valley Fair and attended proms. Unlike other students she didn't date and only "watched" phys-ed class.

After high school it was "off to college" to prepare for the rest of her life. To assist her in being more independent, Linda received an electric wheelchair. Being away from her family in a dorm room at St. Cloud State meant she no longer has someone to dress her morning and evening and to turn her over during the night. She needed an attendant, and a private room next to hers was set aside for that purpose. But how to find such a person!

After some strategizing, Linda decided to look for threesomes in dorm rooms to see if there was an unhappy person who might like a private room. After knocking on several doors only to find contented little trios, she finally found a student who was desperately unhappy with her roommates and jumped at the chance to leave and be Linda's attendant. This student initially was a stranger, but since then it has been her friends who have later become her roommates and paid attendants.

During college she again sought to be a typical student by going to parties and bars, taking spring break trips to Daytona Beach and Orlando, working a part-time job, playing a major role in a stage play on campus, completing an internship and hanging out with friends. Between her two degrees Linda took a year off. She entered and won the Ms. Wheelchair Pageant and travelled around making appearances and giving speeches on disability awareness for a year. To raise enough money to attend the national Ms. Wheelchair Pageant she drove her wheelchair from Anoka to St.Cloud on a very hot day. It took 15.5 hours and raised $2,000, but she risked sunstroke to accomplish it.

Linda's form of muscular dystrophy, one of 40 types, is a deteriorating condition that affects the nerves in the spinal column causing scoliosis as well as weakening the body's muscles. Linda relies on personal-care attendants for bathing, dressing and transferring.

Today Linda lives with two friends, who also serve as attendants, in a St. Paul apartment, has her own accessible van, goes to movies, night clubs and restaurants, and likes to spends time with friends. She is close to her family, and hates Minnesota in the winter. Last year she was the commencement speaker at her high school. This winter she went to Jamaica for a warm vacation. It could be said that Linda enjoys life!

Linda hopes that others with disabilities can "make it" as she has. She doesn't feel sorry for herself. Instead, she's proud of what she's accomplished and hopes she can serve as a role model for others. "You may have to work harder to get something, but it makes you a stronger person," she says.

Linda also has dreams for her future. Her hopes are to own her own accessible home in a warm climate and to complete her Ph.D. Given the barriers she has overcome in the past, there's every likelihood that she will realize her dreams. Good Luck, Linda!

SUCCESSFUL INTEGRATION IN RECREATIONAL SETTINGS: COMMUNICATION, PLANNING AND SUPPORT BUILDING

by Mo Fahnestock, Integration Facilitator-Community Services Developer, ARC Suburban

"Successful" integration is best defined by the satisfaction of all parties involved in the experience. In leisure or educational settings this includes the instructors, the participants with and without disabilities, and the parents. To ensure the best possible experience for all, careful communication, planning and support building must be undertaken before the program begins.

Below are some steps to success that parents, professionals and "Integration Facilitators" have used cooperatively to create opportunities for individuals of all ability levels.

PLANNING

- Find interesting programs, ones that really attract people. There are active, passive, social and educational types of recreation.
- Look around, find out what friends and neighborhood peers of the same age are doing.
- Try lots of activities and try them more than once. Remember, in Minnesota recreational activities are often seasonal so explore both year-around and seasonal pursuits.
- Get on mailing lists for Scouting programs, 4-H programs, recreation centers, teen centers, fishing clubs, hiking clubs, Park and Recreation, and Community Education programs. Save the flyers for the entire year,--they will offer a jump start on next year's planning.

COMMUNICATION

- Contact the provider of the program early, for communication is a key to success.

- Ask about the activities and schedule. Make sure the program is what you are interested in. Programs generally have goals and objectives, sometimes formal, sometimes informal, that the participants are expected to reach.

- Express your expectations, as a participant or a parent with respect to the programs goals, e.g., "John wants to learn skills, have fun, socialize with peers and take part in community outings."

- Find out how experienced the leaders are, both in running the program and in working with participants of all ability levels. Note: the experience of the program leader and the quality of the program are two major indicators of potential success.

- Explain the skills, abilities and prior experiences the individual has had with activities similar to the program's. Focus on the abilities of the individual and be up front about how many of the goals and objectives might be met. Discuss partial participation in activities that may be challenging.

- Describe what supports may be needed and if they already exist. Begin a dialogue on how the supports can be developed, provided and faded out when no longer needed. Remember, start early and plan for success.

(Part 3 on BUILDING SUPPORTS will be printed in the August issue.)

VOLUNTEERS NEEDED FOR METROPOLITAN COUNCIL'S DEVELOPMENTAL DISABILITIES ADVISORY COMMITTEE

The Metropolitan Council is taking applications from Twin Cities Metropolitan Area residents interested in serving on its Developmental Disabilities Advisory Committee.

The volunteer committee advises the Council on the needs of people with developmental disabilities and helps coordinate planning to meet those needs.

The 25-member committee is made up of persons who have developmental disabilities, their parents or guardians, service providers and the general public. Members serve three-year terms. There are seven vacancies to be filled.

The committee usually meets the third Tuesday afternoon of every other month. Members are expected to serve on subcommittees. Members volunteer their time, but may be reimbursed for their expenses.

For applications or more information, call Sandi Lindstrom of the Council staff at 291-6390. Applications are due by Sept. 8, 1989. Appointments will be made by the Council on Sept. 28, and the new terms will begin Oct. 1.

"Developmental disabilities" refer to chronic and severe physical or mental handicaps that are manifested before age 22 and that substantially limit functions in three or more basic living activities.

FOR YOUR INFORMATION

Telephone Assistance Plan

The Telephone Assistance Plan is a program providing assistance for payment of basic telephone rates for persons who meet the income guidelines and are either 65 and over or have a disability. Minnesota statutes require that a household's yearly gross income must not exceed 150% of the federal poverty guidelines. The limits were raised effective Feb. 16.

$ 8,970	Client
$12,030	Client and spouse with minor child
$ 3,060	Add for each additional child under 18 who lives in the household

For further information about the program contact: Donna Hagemeier, TAP Coordinator, Program Supervision Section, Assistance Payments Division, MN Dept. of Human Services, 444 Lafayette Rd, St. Paul, MN 55155-3834. Telephone: (612) 297-4665.

RTB to Hold Public Hearing

The Regional Transit Board has drafted a five-year transit plan. It includes a special section relating to accessibility andtransit services for people who are elderly and disabled. A public hearing to accept comments from the community will be held at 5:30 p.m. July 10 at the Metropolitan Council Chambers, Mears Park Centre, 230 E. Fifth St., St. Paul. Written comments may be sent until July 24 to Virginia Beach, Accessibility Specialist, Regional Transit Board, at the above address. For a copy of the plan, call (612) 297-5353.

CONFERENCES/WORKSHOPS

August 11-13, 1989

The Association for Retarded Citizens (ARC) Minnesota will hold its Conference and Annual Meeting, "Integration: Full Speed Ahead", at the Holiday Inn, 2200 Freeway Boulevard, Brooklyn Center, Minnesota. Magaly Rodreguez-Mossman, lecturer, author, consultant, and agent for social and personal change, will provide the keynote address. Workshops will include issues in education, early intervention, transition from school to community living, and self-advocacy. For more information, contact: ARC Minnesota; 3225 Lyndale Avenue, South; Minneapolis, MN 55408. Tel. (612) 827-5641, or 1 (800) 582-5256.

October 5-6, 1989

"Integration through Collaboration: Retreat on the Mississippi" is the title of a learning retreat designed for general and special educators on techniques for teaching and managing students with diverse special needs in integrated settings. Joan Bigler and Eva Gadberry, professors in Special Education at St. Cloud State University, will serve as faculty for the retreat, which will be held at the River Conference facility near Clearwater, Minnesota. For more information, contact: JOVE Associates; 8811 - 116th Street; Clear Lake, MN 55319. Tel. (612) 253-0658, or (612) 743-3165.

STUDY OF BENEFIT-COST OF SPECIAL EDUCATION UNDERWAY

The Institute on Community Integration at the University of Minnesota has begun a research effort that will examine the outcomes and costs of special education for individuals with disabilities. The research involves contacting former seacial education students (or respondents for them) who have been out of school up to 10 years. At the same time, special education cost data will be collected for their special programs. This research is being funded by the Office of Special Education and Rehabilitative Services of the U.S. Department of Education.

Preliminary findings have been noted from a sample of 500 students. Overall, however, outcomes are somewhat positive. For some populations, efficiency and benefit-cost analyses confirm that current outcomes justify the costs of providing special education services. Former students were fairly competent in their motor, personal, social/ communication, and community skills, and few demonstrated serious maladaptive behaviors. Continuing research and service efforts can contribute to further improving the quality of life for perons with disabilities.

For further information, contact: Institute on Community Integration; University of Minnesota; 6 Pattee Hall; 150 Pillsbury Drive, Southeast; Minneapolis, MN 55455. Tel. (612) 624-4848.

PUBLICATIONS/RESOURCES

Read My Lips: It's My Choice . . ., by William T. Allen, published by the Minnesota Governor's Planning Council on Developmental Disabilities (June 1989). This resource guide covers five ways to help increase the freedom of choice for people with developmental disabilities: assessing needs, planning for services, evaluating services, understanding the service system, and self-advocacy. As the author explains, "It is hoped that the information in this guide is written in a way that is easy to understand. This was done for several reasons: a) so that people with developmental disabilities who read, can read it and use it; b) so that people who advocate for those who cannot read can explain it more easily; and c) so that we can all understand something together." The content focuses not only on helping people with developmental disabilities to become more involved in the decisions which affect their lives, but also on how to foster self-advocacy skills--people speaking up for their own rights in their own individual ways.

Copies are available free of charge by contacting: Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. Tel. (612)

Developing Housing for Persons with Disabilities is a workbook which explains the requirements and procedures of the Housing and Urban Development (HUD) Section 202 program for persons who are elderly and for persons with developmental disabilities. It is intended for use by nonprofit sponsors, consultants, architects, lawyers, and other housing professionals who wish to use Section 202 direct financing and HUD rental assistance to develop shared or independent housing for persons with developmental disabilities. The manual helps the reader through the process of applying for Section 202 funds and includes recently proposed regulations. Available for $60.00 from: Housing and Community Development Resource Center; 7035 Bee Caves Road, Suite 202; Austin, Texas 78746.

296-4018, or (612) 296-9962 (TDD).

INFORMATION EXCHANGE

STATE SUPPLEMENT
July 1989

Developmental Disabilities Program
300 Centennial Office Bldg.
658 Cedar St.
St. Paul, MInnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*

UNITED STATES COURT OF APPEALS REAFFIRMS 'EDUCATION FOR ALL HANDICAPPED CHILDREN ACT,' ESPECIALLY FOR TIMOTHY W.

It was almost a years ago, on July 15, 1988, that District Court found that Timothy W. was not capable of benefiting from special education, and that the Rochester, New Hampshire, School District was not obligated to provide special education under either the Education for All Handicapped Children Act (P.L. 94-142, as amended) or the the New Hampshire statute (RSA 186-C). (Emphasis added.)

Upon appeal by Timothy W., the United States Court of Appeals for the District of New Hampshire on May 24, 1989, reversed the District Court's decision.

Timothy W. was born two months prematurely on December 8, 1975, with severe respiratory problems. Shortly thereafter he experienced an intracranial hemorrhage, subdural effusions, seizures, hydrocephalus, and meningitis. As a result, Timothy has multiple handicaps and profound mental retardation. He is described as having spastic quadriplegia, cerebral palsy, seisure disorder, and cortical blindness. His mother had attempted to obtain appropriate services for him, and while he did receive some services from the Rochester Child Development Center, he did not receive any educational program until the New Hampshire Department of Education required the Rochester School District to place him in an educational program in October 1984. Thus ensued sporadic attempts at educational programming and many evaluations until 1987, when the School District recommended diagnostic placement at the Rochester Child Development Center.

Experts in special education for children with severe disabilities retained on behalf of Timothy had all concluded that he responded to certain stimuli and was capable of learning. For example, Timothy was aware of his environment, could locate different sounds made by a busy box, and had attempted to reach for the box himself. Timothy also could respond to light, familiar voices, touch, taste, smell, pain, and temperature. He could make purposeful movements with his head, and he showed evidence of retaining some higher cortical functioning which indicated that he could learn in certain areas.

On September 15, 1987, the hearing officer in an administrative hearing ruled that Timothy's capacity to benefit was not a legally permissible standard for determining his eligibility to receive a public education, and that the Rochester School District must provide him with an education. On November 12, 1987, the Rochester School District appealed this decision to the United States District Court by filing a counterclaim, and on March 29, 1988, moved for summary judgment. Timothy filed a cross motion for summary judgment. It was soon thereafter that the District Court ruled that Timothy was "not capable of benefiting from special education," and that "an initial decision must be made concerning the ability of a handicapped child to benefit from special education before an entitlement to the education can exist."

Thus, the concluding statements by the United States Court of Appeals on May 24, 1989, played not only a significant role in the future of Timothy W., who had already missed out of years of educational opportunities, but for many other individuals like Timothy througout the United States.

The conclusion of the Court of Appeals reads:

> The statutory language of the Act (the Education for All Handicapped Children Act), its legislative history, and the case law construing it, mandate that all handicapped children, regardless of the severity of their handicap, are entitled to a public education. (Emphasis added.) The district court erred in requiring a benefit/ eligibility test as a prerequisite to

implicating the Act. School districts cannot avoid the provisions of the Act by returning to the practices that were widespread prior to the Act's passage, of unilaterally excluding certain handicapped children from a public education on the ground that they are uneducable.

The law explicitly recognizes that education for the severely handicapped is to be broadly defined, to include not only traditional academic skills, but also basic functional life skills, and that educational methodologies in these areas are not static, but are constantly evolving and improving. It is the school district's responsibility to avail itself of these new approaches in providing an education program geared to each child's individual needs. The only question for the school district to determine, in conjunction with the child's parents, is what constitutes an appropriate individualized education program (IEP) for the handicapped child. We emphasize that the phrase 'appropriate individualized education program' cannot be interpreted, as the school district has done, to mean "no educational program."

SUGGESTIONS FOR FACILITATING CONSUMER FORUMS

The following summary originates from three people, Barbara Blease, Hannah Margolis, and Robert Rosenberg, who provided their ideas and recommendations to the World Institute on Disability in preparation for a series of forums on the quality of life as perceived by persons with developmental disabilities in California. These ideas are offered to others who are planning to sponsor similar forums or public meetings.

The challenge is how to bring together primary consumers in small or large groups, many of them strangers to every other person present, in an unfamiliar environment, and "extract" from them in a few hours of intensive discussion cogent commentary and recommendations relating to the quality of their own lives.

A further requirement is that this information be focused on particular dimensions of their lives: living circumstances; where and under what circumstances they work or otherwise pass the time of day; the nature of their personal relationships, from the most casual to the most intimate; how and under what circumstances they access recreational opportunities. "This too presents a significant challenge to people who have been 'licensed' by the labels put on them to practice intellectual laziness," observed the authors.

Of central concern is how to enable, or facilitate, primary consumers to address issues forthrightly without the fear of reprisal from professionals in the service system. Another concern is the reassurance of persons who are willing to speak that they will be taken seriously and that their comments will be respected. Such reassurance is needed, such as, when statements may not be entirely understood on first hearing, it is important that appropriate efforts will be made to achieve clarification and understanding of such remarks.

The central objective of such an undertaking is to help people with cognitive impairments learn to speak up for themselves, to learn how to express their needs, wants and opinions, and of ultimate importance, to gain control over the conduct and direction of their own lives.

A major recommendation is that the facilitation of forum participants be entrusted basically to primary consumers who are experienced in the public discussion process and who are good role models. They are the energizers and enablers and are absolutely central to success in gathering meaningful consumer input.

Preparation

Site:

*Hold the forum close to where most people who will be attending live. With respect to the physical site, it goes without saying that the same considerations of accessibility, adequacy of services of size of population, and valued ambience of the facility itself should be taken into consideration and studied in 1advance as for any public meeting of perons with disabilities.

Networking/Promotion of Participation:

*Identify local resource people who will and can make a commitment to get people to the meetings and establish personal relationships with them. Seek those who are recommended by knowledgeable people from that particular community, those who have a high commitment to consumer empowerment.

*Identify, recruit, and prepare primary consumer leaders.

*All written materials for local distribution should convey the idea of influencing primary consumers to participate actively and to express their true and innermost feelings regarding aspects of and issues in the quality of their lives.

Transportation:

* Beyond the usual set of problems around transprotation, a main consideration should be to gain some measure of control over the conditions of transportation of primary consumers to and from the forums. "Transportation to" is largely self-explanatory, although getting people there on time can be a problem. Based on previous experiences, it is the "from" that needs to be emphasized. Nothing can be more disruptive than the arrival of transportation providers in the middle of a conference, to take people away. This is usually due to rigidly specified contracts held by chartered carriers, limited hours of service by paratransit systems, and by residential staff who have accompanied the primary consumer and have placed their own schedule considerations ahead of the forum's needs. Overtime pay may influence such transportation considerations.

Format

Role of Primary Consumers:

There is a significantly growing cadre of primary consumer leaders from the self-advocacy movement that can serve as enablers. They have been known to demonstrate exquisite skills in providing support and reassurance to people who are not used to or confortable with speaking up. "They are the role models of classic proportions, and there is no question of their integrity if they are selected for their devotion to independence and integration," the authors stated.

The tone of the forum can be set when the primary consumer leaders are there to greet the people when they arrive. This approach has been known to inspire and "give permission" to speak and speak freely to consumers who have spent most of their lives being told what to do by non-consumer authority figures.

In a large group meeting, set up the microphone, if used, in such a way that one or more primary consumers can sit next to the speaker and assist in a variety of ways (e.g. adjusting the microphone, helping people to sit and/or stand, simply touching, or otherwise reassuring a speaker with "stage-fright"). In a small group meeting, have experienced persons sit within whispering distance of others who are new to the process.

For large group forums, prepare several primary consumers, with at least one from the locale, to sit on a panel with persons who are non-cognitively disabled to ask questions of persons who are testifying, when such questioning seems appropriate to expand or clarify information being provided. The inclusion of primary consumers on such a panel will further intensify the speakers' sense of validation and acceptance. Often it is the communication between consumers that clears the way for provision of additional information that might otherwise be lost or withheld.

Role of Non-consumers:

These individuals need to be shown how to be unobtrusively available to provide support and reassurance. Clearly, it would be counterproductive for non-consumers to present themselves, even unintentionally, in a manner that might be interpreted as confrontational, threatening, or intimidating. Reasons for this include: (1) some primary consumers may be afraid that their negative statements regarding the conditions of their lives will get back to their caregivers, and (2) there will undoubtedly be expressions of great emotion, expecially anger, grief, and frustration. Given the difficulty with expressive communications experienced by many of these same consumers, emotional outbursts are often perceived as attacks by professionals, parents, and other persons involved with the system, and responded to accordingly.

The authors will be happy to communicate with interested parties by mail or phone regarding their ideas. Addresses and phone numbers are available from the World Institute on Disability, 1720 Oregon, Suite 4, Berkeley, CA 94703. Tel. (415) 486-8314.

Finding Services for Children with Developmental Disabilities and Special Health Care Needs

The National Information Clearinghouse for Infants with Disabilities and Life-threatening Conditions is an information and referral system that provides current information about community services and resources throughout the United States. A specialist is available by way of a toll-free number to answer questions and identify organizations within your area or anywhere in the country to provide the services needed. Call: 1 (800) 922-9234.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

LENDING LIBRARY SELECTIONS

With a Little Help from My Friends, is a one-hour videotape (VHS, 1/2 inch)about creating schools where all students belong and learn together. It was produced by Marsha Forest and George Flynn. Three sections include: 1) "The Vision"-- Judith Snow, Marsha Forest, and the students and staff of St. Francis School, Waterloo Region Separate School Board, Kitchener, Ontario; 2) "Let's Talk"--students and staff discuss what integration has meant to them; and 3) "May's Map"--an example of planning curriculum that builds schools that are inclusive. "Just watch these kids," said Robert and Martha Perske from Connecticut, "and listen to their wisdom. They possess the wisdom for a new age." This videotape is also available for purchase: price is $50.00, plus $5.00 shipping, from: Expectations Unlimited; P.O. Box 655; Niwot, Colorado 80544. Tel. (303) 652-2727.

They Don't Come with Manuals, (VHS, 1/2 inch, 20 minutes), produced by Community Services Information Group for the Louisiana Division of Children, Youth and Family Services, 1988. Adoptive and foster parents share their experiences as parents of children who have disabilities. The importance and advantages of children growing up in permanent homes is stressed.

In the Sunshine (VHS, 1/2 inch, 14 minutes), produced by the Association for Retarded Citizens of Minnesota, 1989. Filmed in various locations in Minnesota, this production depicts the quality of life for individuals with multiple disabilities who have moved from state operated regional treatment centers to homes in community settings. Parents testify that their sons and daughters are "better off," get closer supervision, have more opportunities to make choices, and are more involved by doing things for themselves.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

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If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street, St. Paul, MN 55101

(TIME-DATED MATERIAL)

DIRECTOR 607
GOVERNOR'S PLANNING COUNCIL
ON DEVELOPMENTAL DISABILITIES
300 CENTENNIAL BLDG
ST PAUL MN 55155

D D INFORMATION EXCHANGE

Published monthly by the Developmental Disabilities Program of the Metropolitan Council
Editor: Kay Zwernik

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Vol. 14, No. 8
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VOLUNTEERS NEEDED FOR METROPOLITAN COUNCIL'S DEVELOPMENTAL DISABILITIES ADVISORY COMMITTEE

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The volunteer committee advises the Council on the needs of people with developmental disabilities and helps coordinate planning to meet those needs.

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The committee usually meets the third Tuesday afternoon of every other month. Members are expected to serve on subcommittees. Members volunteer their time, but will be reimbursed for their expenses such as parking and transportation.

For applications or more information call Council staff Kay Zwernik at 291-6364 or Edith Watson at 291-6427. Appointments will be made by the Council on Sept. 28, and the new terms will begin Oct. 1.

"Developmental disabilities" refer to chronic and severe physical or mental handicaps that are manifested before age 22 and that substantially limit functions in three or more basic living activities.

SUCCESSFUL INTEGRATION IN RECREATIONAL SETTINGS: COMMUNICATION PLANNING AND SUPPORT BUILDING---PART THREE

by Mo Fahnestock, CTRS, M.Ed., Integration Facilitator-Community Services Developer, ARC Suburban, Burnsville, MN

(Parts one and two of this short paper were published in the June 1989 issue of the Information Exchange. Part three is the final section. Parts one and two covered communication and planning.

BUILDING SUPPORTS

- Supports should be as unintrusive as possible to the program, the other participants and to the individual using them.
- The goal of using supports is to phase them out, as much as possible, when the individual in his/her environment demonstrates the ability to do the activity without the support.

- Examples of supports include: one-to-one aide (for the participant with a disability); program aide (for all participants); friend or peer assistance; modified equipment; modified rules; reordering the curriculum; and task-analyzing the activity.

- Use the principle of natural proportions. In the community, there is approximately one person with a disability to ten people who do not have a disability. So, when planning a program, try not to exceed two or three participants with disabilities in a ten-person program.

- Friend or peer assistance should utilize more than one friend. Rotate peer assistants every five or ten minutes so that each assistant can have a chance to do their own work and participate alongside everyone else. This will also allow more peers to get to know the participant with a disability.

- Teach all the participants to offer each other assistance in the following way. If a friend is having problems, first, explain the directions, then demonstrate how to do it and finally, if needed, assist using a hand-over-hand technique. This is a wonderful gentle teaching process.

- <u>Finally, nothing is more important than how the leader expresses value for each participant.</u> Everyone involved responds positively or negatively to the leader's behavior towards each participant. If the communication is clear, free flowing and equal between the leader and all participants, the environment of the program will foster socializing and the inclusion of everyone.

FOR YOUR INFORMATION

Eligibility Threatened by New Program

Individuals who have disabilities, work and receive Medical Assistance may be significantly affected by recent legislation passed by Congress. The Medicare Catastrophic Coverage Act of 1988 now being implemented may make individuals ineligible or may result in a significant increase in their spend-down. The legislation greatly narrows eligibility by eliminating and restricting the types of deductions a state can allow a working person with a disability to use in determining eligibility. Certain deductions which were previously allowed, such as state and federal taxes, would no longer be allowed to be deducted in determining eligibility. People who are affected by the implementation of this Act and other interested people are currently working to change and challenge the implementation of the Act though legal action. People who would like to assist in this effort may contact Dan Klint, 1701-113th Ave., #102, Coon Rapids, Mn 55433 or phone (612) 754-3031.

New Master's Level Program Available

A new master's program in the Twin Cities, of particular interest to workers in the human services, is the Master of Arts in Developmental Disorders at St. Mary's College Graduate Center in Minneapolis. This program began in 1985 on the Winona campus of St. Mary's, but it moved to its Minneapolis location in the fall of 1988. The interdisciplinary program, one of eleven offered at the Graduate Center, is designed to meet the needs of professionals who work in a variety of settings that serve individuals with developmental disabilities or disorders.

The program is attracting professionals who work in settings such as: residential settings for children or adults, crisis centers, community outreach programs, special education support services, and family services for individuals who have developmental disabilities. Individuals usually choose this program to broaden their knowledge in the field, enhance their personal and professional development, or advance their career options. Late afternoon and evening classes are scheduled at times convenient for working adults. Students may be accepted into the program at any time during the academic year. For more information, call the St. Mary's College Graduate Center at (612) 874-9877.

Leisure Specialists Meet

An Integration in Leisure Settings group has begun to meet on a regular basis to provide an opportunity to network, exchange information and hear speakers or topical open forums on the process of integration in recreational settings and programs. Recreation professionals and others who are contemplating planning or practicing the provision of integrated recreation for both children and adults are invited to attend the meetings. The group also has begun a library of pertinent resources on integration. The group meets in the morning of the fourth Tuesday of every month at different locations in the Metropolitan Area. For more information or to add your name to the mailing list, contact Mo Fahnestock at ARC Suburban (612) 431-3700.

Research Program Request Volunteers

The Institute for Disabilities Studies at the University of Minnesota is seeking individuals with developmental disabilities to serve in research on therapy programs and the learning of new adaptive skills. This research is carried out as a part of the Institute's primary mission to serve people with developmental disabilities by conducting basic and applied research into the nature of such disabilities and the effectiveness of current treatment approaches. One study requires individuals whose therapy includes the use of a neuroleptic drug such as Haldol, and it will seek to determine the drug dosages at which maladaptive behavior is reduced without impairing the learning of new adaptive skills. A second study requires individuals who engage in persistent self-injury, and it will examine a promising new drug therapy that has recently been shown to reduce self-injury without side effects. For more information about this research or about the Institute, call Dr. Daniel Cerutte at (612) 627-4506.

EMPLOYMENT OPPORTUNITIES

Employment Specialist

A progressive employment service for persons with developmental disabilites is seeking individuals to do JOB COACHING. Responsibilities include training and supervising persons with developmental disabilities at community jobs. Experience with persons with mental retardation or industry-related jobs preferred. College credits or AA degree desired. Full-time and on-call positions available. Send resume to: Kaposia, Inc. 380 E. Lafayette Freeway So., St. Paul, MN 55107-1216. Att: Director of Human Resources.

Associate Psychologist

The Technical Assistance Program at the Institute for Disabilities Studies has an opening for an Associate Psychologist with a minimum of three years post-Ph.D. experience and LCP license. The individual will serve as administrator of the Institute's multidisciplinary community-based service programs for people with developmental disabilities and severe behavior problems. Experience working with behavioral and bio-medical professionals is required. For additional information on the above position, contact Mary Piggott at the Institute for Disabilities Studies at (612) 627-4500.

PUBLICATIONS

Ombudsman Office Brochure

The Office of Ombudsman has produced a brochure for distribution. The brochure describes the function of the Office of the Ombudsman for Mental Health and Mental Retardation and outlines the kind of action that can be taken in response to a complaint received by the Office. The telephone numbers of the St. Paul office and all of the regional offices are listed.

A copy of the brochure, with an order form for additional copies, has already been sent to each residential facility and DAC in the state, and advocacy groups. To obtain a copy, call Cynthia Pederson at (612) 296-3848 or call toll-free 1-800-652-9747.

Persons with Profound Disabilities---Issues and Practices

A new book, edited by Fredda Brown and Donna H. Lehr, dealing with a population of people not frequently addressed in the literature, has been published. Titled, *Persons with Profound Disabilities---Issues and Practices*, the book combines the writing of some of the most well-known experts, teachers and writers to bring together papers on people with profound disabilities. This group of people has previously been served in institutions and other segregated settings. The editors note that while we have made significant gains in teaching people with severe disabilities, there still is a great need for development in applying those concepts and principles to this population. They acknowledge that many issues exist such as quality of life that need to be addressed in order to better understand and meet their needs.

The book begins by discussing some of the issues currently facing professionals in the field, reviews the available research and laws, and provides comments on integration of students with profound disabilities into public schools. Other chapters cover educational considerations such as complex health needs, motor and communication development, choice making, programming for young children and school-aged children, vocational training and residential services. Two Minnesota professionals are contributors to this book. They are Joe Reichle and Jennifer York, both of the University of Minnesota Institute on Community Integration.

The book may be ordered from Paul H. Brookes Pub. Co., P.O Box 10624, Baltimore, MD 21285. The order number is #0158. The price is $30.

Appliance Instruction for People with Visual Impairments

Manufacturers have for years included use and care guides and cookbooks with major home appliances. These publications, printed in standard sizes and there are millions of consumers with visual impairments for whom the standard publications serve little purpose.

The Whirlpool Corporation has offered for the past several years instructions and cookbooks in Braille, large type or audiocassette formats to their appliance owners. The following are offered as a service to consumers. Each price includes shipping charges.

Whirlpool Micro Menus Cookbook--Tested with 6-700 watt microwave ovens, this cookbook contains basic microvave cooking directions, cooking tips and more than 220 recipes. Available in Braille (6 volumes), $20; large type (1 volume), $15; and audiocassette (8 in album holder), $30.

The Cooking Guide--This book contains generic information about cooking with electric ranges, plus a variety of tips for baking, roasting, broiling and rotisserie cooking. Cost is $4 for either Braille or large-type editions.

The Laundry Guide--This booklet includes information on preparing clothes for washing, laundry aids, stain removal and common washing problems. Cost is $3 for Braille or large-type editions.

The Dryer Guide--This booklet offers instructions on sorting loads for drying, drying special items and how to determine drying times. Cost is $2 for Braille or large-type editions.

Order any of the publications from Appliance Information Service, Whirlpool Corporation, Benton Harbor, MI 49022.

CONFERENCES/WORKSHOPS

September 14-15, 1989

A two-day symposium to be held in Minneapolis will focus on ***"Creative Options for People with the Most Severe Disabilities."*** Nationally prominent leaders in the field who creatively address the needs of working with people with severe disabilities will be featured. Included are such names as Arlene Aveno, Paul Bates, Fredda Brown, Steve Calculator, Wade Hitzing, Ed Roberts, Joanne Sowers and Jeff Strully. Topics for the symposium will include: preparing and connecting with communities; supported employment for people with physical/multiple disabilities; vocational options; communicative behavior strategies; strategies to allow clients more environmental control; developing staff competency; and more. The symposium is sponsored by the Minnesota Habilitation Coalition, Region 10 service providers and the Albert Lea Technical College. It will be held at the Minneapolis Hilton Inn, 1330 Industrial Blvd., Minneapolis from 9 a.m. to 4:30 p.m. on the 14th and 8:30 a.m. to 1:30 p.m. on the 15th. The fee is $85 and payable to Albert Lea Technical College. Mail to: Albert Lea Technical College, Att: Sharon Jahnke, 2200 Tech Drive, Albert Lea, Mn 56007. The registration deadline is Aug. 31. For more information, call Jeanne Snyder at (507) 373-6064.

October 7, 1989

An ***"Accessibility Fair"*** will be held at the Northland Inn, Brooklyn Center, (I-694 and Boone Av.) from 9 a.m. to 5 p.m. The fair is being organized by the Access Resource Network and is free to the public.

A series of informative workshops, designed for consumers and professionals who deal with handicap accessibility issues, will be held. The workshops will cover topics including legal requirements, community issues and practical recommendations for the home. Additionally, an extensive array of exhibits by area vendors will feature products used for access, recreation and daily living aids. Displays by service providers, referral sources and funding agencies will round out the comprehensive list of available information sources.

The Fair precedes the evening "Minnesota Access Achievement Awards" recognition program taking place at the Inn under sponsorship of the Minnesota Multiple Sclerosis Society. For further information on the "Accessibility Fair," contact Shannon McGurran or Coral Shanahan at (612) 520-0518. For more information and nomination forms for the awards program, contact the Minnesota Multiple Sclerosis Society's Access Minnesota project at (612) 870-1500.

October 11-12, 1989

"Return Us the Children: Prevention and Early Intervention in Developmental Disabilities" is the theme of the second annual conference sponsored by the Institute for Disabilities Studies. It will be held at the Radisson Minnetonka in Minnetonka, MN.

The purpose of the conference is to present current research and clinical and program strategies aimed at preventing developmental disabilities and minimizing their impact on children and families at risk. Major speakers will address issues such as fetal alcohol syndrome, nutrition, maternal cocaine abuse and early education intervention. The conference is directed toward persons working in education, public health, medicine, nursing and community agencies.

Complete program information will be available in the September newsletter.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
August 1989

Developmental Disabilities Program
300 Centennial Office Bldg.
658 Cedar St.
St. Paul, MInnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
(612) 296-4018

SUPREME COURT ISSUES DEATH PENALTY DECISION

The United States Supreme Court announced its decision on June 26, 1989, in the case of Penry v. Lynaugh, a Texas case concerning the constitutionality of imposing the death penalty on convicted criminals with mental retardation. The Court held that the Eighth Amendment bar on "cruel and unusual" punishment does not categorically prohibit imposition of the death penalty on people with mental retardation.

The case involved Johnny Paul Penry, whose I.Q had been measured at various times in his life with scores between 50 and 63. He was convicted of a 1979 murder in Texas and sentenced to death. The death sentence was affirmed by Texas appellate courts and the U.S. Court of Appeals for the Fifth Circuit, none of which h mental retardation.

The Surpreme Court reversed Penry's death sentence and sent his case back to the trial court for re-sentencing. In an opinion by Justice Sandra Day O'Connor, the Court held that Texas law had not given the jury adequate opportunity to consider the importance of Penry's mental retardation in the selection of an appropriate sentence of his crime.

The Court held that Penry's mental retardation was relevant to the level of his personal blameworthiness. "Because Penry was mentally retarded, and thus less able than a normal adult to control his impulses or to evaluate the consequences of his conduct," properly instructed jurors could "conclude that Penry was less morally culpable than defendants who have no such excuse," wrote Justice O'Connor.

In another portion of its decision, the court declined "at present" to rule that the execution of individuals with mental retardation is always prohibited by the Constitution. Justice O'Connor indicated that the door is not closed for future reconsideration of the constitutionality of the death penalty for people with mental retardation. The Court will look to actions of Congress and particularly the state legislatures for evidence of an evolving consensus before it would determine that imposing the death penalty on all people with mental retardation is cruel and unusual punishment. Justice O'Connor wrote, "The public sentiment expressed in these and other polls and resolutions may ultimately find expression in legislation, which is an objective indicator of contemporary values upon which we can rely. But at present, there is insufficient evidence of a national consensus against executing (people with mental redardation who are) convicted of capital offenses for us to conclude that it is categorically prohibited by the Eighth Amendment."

The Court has left an unusually explicit opening to bring the Eighth Amendment issue back to court when more states have considered the issue. Since arguement in the Penry case, the Maryland legislature has agreed to ban the execution of people with mental retardation. The American Bar Association has also endorsed this position.

WISCONSIN IDENTIFIES 'THE ACTIVE TREATMENT MYTH'

Recently the Wisconsin Coalition for Advocacy, the protection and advocacy agency for persons with developmental disabilities and persons with long-term mental illness, released a report based on three years of analysis. The report is entitled, The "Active Treatment" Myth: People with Developmental Disabilities Trapped in Wisconsin Institutions (May 1989). Following are some highlights from the report.

"Wisconsin, despite its progressive human service reputation, has continued to keep a large number of people with developmental disabilities in institutions. (Current social policy) is responsible for the segregation of thousands of our fellow citizens long after many other states committed themselves to moving institutionalized persons with developmental disabilities back to their communities. It has also led to a gross misuse of Wisconsin and federal tax dollars--spending millions of dollars for people to live in places where they should not be."

"The crisis of the moment," the report continues, "has been precipitated by vigorous enforcement of federal active treatment standards by the federal Health Care Financing Administration (HCFA) in the state Centers for persons with developmental disabilities, in intermediate care facilities for persons with mental retardation and related conditions (ICFs-MR), and in general nursing homes. The increased enforcement activity has led to the disclosure of widespread, ongoing violations of active treatment requirements througout the state."

"Active treatment" is defined as: "aggressive, consistent implementation of a program of specialized and generic training, treatment, health services, and related services . . . directed toward: (1) the acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and (2) the prevention or deceleration of regression or loss of current optimal functional status."

"The facilities that fail to meet these requirements face the possible loss of federal funds," the report points out.

"It should be noted," the report continues, "that it is not the fault of the federal government that many facilities in Wisconsin fail to meet many of these requirements, nor is the federal federal government forcing Wisconsin to spend more money in these facilities to correct these problems, rather than to move people to the community. It is the state which has chosen, on its own, to respond to this crisis in such an imbalanced way: pouring large amounts of funds into "fixing" institutions housing substantial numbers of people, but failing to simultaneously fund the community alternative which many of these people could utilize and which could greatly reduce the need to use institutions.

"Although the active treatment requirements do have some merit," said the authors of the report, "this merit is generally in the area of improving a person's 'condition of confinement.' In other words, the overall thrust of active treatment does not really promote such concepts as normalization, community integration, least restrictive environment, living in a 'valued home,' etc."

The report contains a comparison between the major concepts of active treatment and Wisconsin's officially-adopted policies and goals for persons with developmental disabilities. "Since Wisonsin policies are heavily based (at least on paper)," continued the authors of the report, "on the principles of normalization and community integration, this comparison in effect shows the contrast between federal active treatment concepts and progressive values and practices in our field in general:

1.**Wisconsin Goal:** "Integration into the community's mainstream," (including the objectives of): "placement in the least restrictive environment"; and (returning) "persons with developmental disabilities to the community when their needs can be met at the local level."

Active Treatment Requirment: No reference to 'least restrictive environment' except to clarify that it is not required; marginal references to off-grounds activities and helping residnets develop skills they will eventually need for community life.

2.**Wisconsin Goal:** "A valued home in the community" (including the objectives of): "movement to less structured living in smaller facilities or individual residences"; and "blending in with appropriate neighborhoods."

Active Treatment Requirement: No reference to a 'valued home' (or even a similar concept); no requirement or preference for small residences or "blending in with appropriate neighborhoods."

3.**Wisconsin Goal:** Emphasizes "skills, behaviors, and service settings which foster maximum feasible participation in community life" (including the objectives of): "services designed and modified to 'fit the person'"; and (participation) "in valued roles in society, such as work or schooling in community settings."

Active Treatment Requirement: Requires individualized program plan focused on the development of skills and behaviors necessary for independence; but ignores fundamental learning principles by trying to teach these skills and behaviors in isolation from the community.

4.**Wisconsin Goal:** Enabling people to be "part of a network of personal relationships with valued people" (including the objective of): "contact between people requiring long-term support and others not requiring this support."

Active Treatment Requirement: No requirement to actively promote personal contact or residents' relationships with people outside the facility; client protections include rights to communicate and associate freely with the outside world.

5.**Wisconsin Goal:** Achieving "maximum feasible control over their onw lives" (including the objectives of): "the same rights as other citizens"; and (placing) "the least possible restriction on personal liberty and exercise of Constitutional rights consistent with due process."

Active Treament Requirement: Several important rights included in Medicaid regulations, but generally they are the rights of people who are kept behind closed doors; many rights afforded most citizens are not included.

The report concluded:

1. There is some merit to active treatment: if institutions comply with these standards, each resident will have an individual program plan and residents may have less "dead time" than when they were living in facilities not providing active treatment.

2. However: Focusing our primary attention on active treatment compliance does not fit with--and diverts us from--our state's officially-adopted goals for persons with developmental disabilities: adequate and appropriate support for people to live in the community, as valued

citizens in their own homes and neighborhoods. Adding funding to provide active treatment cannot change the fact that (State) Centers, nursing homes, and large ICFs-MR are still institutions, nor can it change the fundamental reality of life for institutionalized persons with developmental disabilities: institutions are and will remain inappropriate and often inhumane environments, regardless of the time and money we pour into them; and

Active treatment is internally inconsistent--it aims to teach skills for community life in isolation from the community, consequently eliminating most or all opportunities for natural use of these skills; and it attempts to change 'inappropriate behavior' in an institutional environment which may itself be a major cause of this behavior.

3. Consequently: We must renew our commitment to the integration of institutionalized persons with developmental disabilities into their home communities, a goal which has already been shown to be attainable in Wisconsin;

We must finally translate this commitment into concrete policy and fiscal actions which move large numbers of people out of institutions and ensure adequate support for them in the community; and lastly. We must find ways to meet active treatment requirements without expanding and legitimizing institutions in Wisconsin.

Copies of the report and/or the Executive Summary may be requested from: Wisconsin Coalition for Advocacy; 16 North Carroll Street, Suite 400; Madison, Wisconsin 53703. Tel. (608) 267-0214.

GOVERNOR'S PLANNING COUNCIL RECOMMENDS GRANT AWARDS

On June 7, 1989, the Governor's Planning Council on Developmental Disabilities recommended approval of nine applications for grants. A total of 34 applications were received in response to a Request for Proposals issued earlier this year. Each application was reviewed, evaluated, and scored by the Grant Review Committee of the Council. Following is a brief summary of the applications that were recommeded for funding.

Advocating Change Together and People First: The Committee recommended that the two applicants work together to establish two new chapters of consumer organizations in Greater Minnesota. The work program would provide training for new chapters.

ARC--St. Paul: This project will develop a coordinated community leisure service system that is open, integrated, and accountable to persons with developmental disabilities and their families. The project will look at the use of "free-time" by 14 to 21 year old youths who have a disability. Generic program staff will receive technical assistance and support to make programs and settings accessible. Youth and their families will receive empowerment training. A model process detailing these and other approaches will be published.

Dakota County Human Services: A voucher program will be implemented in which ten families in Dakota Couty with children with developmental disabilities will be given full authority and responsibilitiy of County funds already budgeted for them. Vouchers will be used to purchase goods and services needed by the these families.

Epilepsy Foundation of Minnesota: This grant will enable the Foundation to expand Training and Placement Services (TAPS) in the Twin Cities Metropolitan Area to minority persons over age 18 who have epilepsy. Outreach would be carried out in the black and hispanic communities.

Human Services Research and Development Center: This project will target six individuals in each of five-county or multi-county areas and institute procedures that would attempt to integrate targeted individuals more fully into their local communities. In addition, Personal Futures Planning (PFP) would be offered at five sites in Greater Minnesota.

Institute on Community Integration: This project will replicate the Parent Case Manager program with 45 parents in Greater Minnesota. The parents would receive training in a number of areas that will enable them to become more fully involved in the selection and contracting for services for their family member with a developmental disability.

Kaposia, Inc.: This project will implement the Career Planning Process with 10 persons in the Twin Cities Metropolitan Area and 10 persons in Greater Minnesota. The Career Planning Process is a variation of Personal Futures Planning that focuses on employment and career planning. Workshops and informational meetings will be held and staff in five agencies will be trained in the use of the technique.

World Institute on Disability: This project will replicate the Partners in Policymaking project for 35 persons most of whom will be consumers. Participants would be recruited from throughout Minnesota and attention would be paid to obtaining a mix of age, sex, place of residence, economic status, race and disability. Eight two-day sessions will provide information on leadership training, and state-of-the-art services to persons with disabilities.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

LENDING LIBRARY SELECTIONS

Partnership for Quality Services: Keeping the Quality of Life Growing, Volunteer Monitor's Handbook and videotape, Association for Retarded Citizens of Minnesota, 1988. Partnership for Quality Services is a volunteer monitoring project designed to ensure and promote quality services for persons with developmental disabilities. This project, funded in part by the Minnesota Governor's Planning Council on Developmental Disabilities, demonstrated how consumers of services, members of the community, and professionals can work together to develop quality programs and assure that people with disabilities can lead valued lives in the community. Volunteer monitors address quality of life issues, such as community participation and personal relationships. The monitor's handbook, used in training of volunteers, provides basic values based in principles of normalization, the monitor's responsibilities, and policies and procedures for implementing change. The videotape has two segments: 1) an overview of the project; and 2) simulations of monitoring visits to community programs, depicting each quality of life indicator in detail.

VIDEOTAPES AVAILABLE ON LOAN (VHS 1/2 inch):

Don't Be Surprised! (20 minutes) National Association for Down Syndrome. A panel of experts, adults who have Down Syndrome, tell about their life experiences--their likes and dislikes, their successes and failures, and best of all, their positive outlook via a sense of humor. These individuals, who were once described at birth as "hopeless candidates for institutionalization," are shown as they are today--working at real jobs, living independently, and fully participating in and contributing toward life in their communities.

Regular Lives (28 minutes & 33 seconds) State of the Art Productions for Syracuse University, 1988. Children with developmental disabilities participate in typical school settings, an affirmation that integrated classrooms can work. This production is intended to educate the general public, parents, and teachers about the values and advantages of including children rather than excluding and segregating them because of their disabilties.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

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REALIZING THE VISION ACCOMPLISHMENT

Loving the Peace and Quiet

It was a beautiful June day, sunny and hot, but not too hot. Steve was celebrating his 38th birthday and agreed to let me take him out to breakfast while he told me about his travels through life. Steve has been around long enough to see the many changes in our human service system and what it has to offer to people with developmental disabilities. In fact, he has actually experienced much of the system himself.

At the time Steve was born, out-of-home placements for children with developmental problems were very common and often done at the recommendation of the family physician. Steve was also placed in a home. He first went to the Sauk Center home for children as a baby and several years later to Cambridge, a public institution, where he stayed until he was 17. He still remembers that the "food wasn't good." His work was changing curtains, scrubbing floors and moving furniture.

From Cambridge he was sent to a small community west of the Twin Cities where he lived in a typical group home, attended a typical DAC and later a typical sheltered workshop. Steve recalls that his work then consisted of assembly, and he feels that he didn't learn anything he could use in a community job. At that time, he really wanted to move to the Cities where he felt there was more to do and where he would have a better chance to find a job.

Six years ago, Steve had that opportunity. Steve moved to the Metropolitan Area and began working for a time in another sheltered workshop. After a while he was offered work for a new company in the house cleaning business. Like many new businesses, this one also went bankrupt.

After moving to the Twin Cities, Steve lived in a cluster home with five other men, all of whom were virtual strangers. A cluster home is set up to teach independent living skills with the goal of living on their own ultimately.

Finally in February 1988 Steve was able to move to his own apartment in West St. Paul with a friend. His life finally became his own. After all the years of moving in and around the human service system in Minnesota, Steve, at age 36, finally achieved the independence he wanted and needed in order to fulfill his dreams.

Today, Steve has a full-time job cleaning a government building in downtown St. Paul. He has a HUD apartment in a very nice building with a swimming pool that he likes to use. He is doing very well with only four hours of Semi-independent living services (SILS) a week.

Living on his own enables Steve to keep his own checkbook, keep on a diet that has helped him lose 20 pounds, make his own doctor and other appointments, and plan his own social activities. He belongs to a "breakfat club" that meets once a week. He cleans his half of the apartment and cooks his own meals since his roommate has a different working schedule.

Steve says it feels good to be on his own; he likes making his own decisions. But one of the best things about having his own apartment is the peace and quiet he enjoys. There's no more shouting and arguing which normally happens when you live with unrelated people in one home. Steve's even considering becoming his own guardian, perhaps his final step to true independence.

FOR YOUR INFORMATION

Resource Fair to be Held

Parents and professionals concerned with young children who have special needs will receive information about available community services Thursday, Sept. 28 at 3-9 p.m. in a Resource Fair at the Har Mar Mall in Roseville. Representatives from public and private health, education and human service agencies will be available to describe programs for infants and children through age five who can benefit from early intervention services. There is no charge for the fair. The fair is sponsored by the Interagency Early Intervention Committees (IEIC) of Ramsey County.

Job Fair to be Held

The Job Placement Division of the Minnesota Rehabilitation Association is sponsoring a statewide Job Fair for persons with disabilities on Friday and Saturday, Oct. 6-7 in the new Minneapolis Convention Center. All people with disabilities are invited to attend. There is no fee for participants. Applicants must be able to interview independently with employer representatives. Professional staff serving persons in Supported Employment Programs will be on hand to explain the benefits of these programs to participating employers. Interpreters for people with hearing impairments will be provided. Braille materials will be made available upon a 30-day advance request. Approximately 70 employers will be present at the two-day event.

Applicant packets will be sent to interested organizations or potential applicants. The packets include a Job Fair fact sheet and an application form. Advance applicant registrations must be received by Sept. 11. Applications will also be accepted at the door during the fair. A completed application is necessary for admission to the fair. Listings of types of jobs available from the employers will be at the registration desk. To obtain Applicant Registrations Packets or for further information, contact: Cliff Miller, 1989 JPD Job Fair, 390 N. Robert St., St. Paul, MN 55101 or 612- 296-5646 V/TDD.

Awards Given

The Association for Retarded Citizens Minnesota presented awards of recognition/appreciation to area individuals/businesses at its annual conference held Aug. 11-12 in Brooklyn Park. Shellie Hendricks, St. Paul, received the Citizenship Award. Ms. Hendricks is employed at Western Life Insurance Co. and has volunteered at ARC-St. Paul. She lives independently and is a member of the State Commissioner's Task Force for Persons with Developmental Disabilities. Anne Murray received the Family Advocacy Award. Ms. Murray is a parent of a child with disabilities, is active with several parent organizations including Pilot Parents-St. Paul and PACER Center. She is an ARC St. Paul Board member. She also helped found Advocates for Integrated Options to rally support for the Department of Human Services Regional Treatment Center proposal. Kowalski's Market received the Employer of the Year Award. Kowalski's was recognized as an employer having an exceptional record for providing supportive employment opportunities for people with developmental disabilities. Kowalski's two grocery stores in St. Paul have hired people with developmental disabilities as maintenance workers.

EDUCATIONAL OPPORTUNITIES

Interdisciplinary Courses on Developmental Disabilities Offered

The Institute on Community Integration at the University of Minnesota is offering four courses on developmental disabilities taught from an interdisciplinary perspective this coming year.
All are three credit courses.

The course on Contemporary Services for Persons with Developmental Disabilities (EPsy 5710)will be offered fall quarter with Jennifer York as instructor.

The survey course focuses on the characteristics and service needs of persons with substantial developmental disabilities using multi-disciplinary approaches; and addresses changing concepts, models of service, issues related to promoting the independence, productivity, and integration of persons with developmental disabilities into the community.

Family-Professional Planning for Persons with Severe Handicaps (EPsy 5609) offered winter 1990 will have Terri Vandercook as instructor. This interdisciplinary course examines the needs of families including children with severe handicaps with emphasis on life cycle needs, service issues and programs of support from infancy through adult years, services from different agencies and disciplines and professional requirements and responsibilities in serving families.

Services for Persons with Developmental Disabilities: Research and Policy Analysis offered winter 1990 will have Robert Bruininks as instructor. Interdisciplinary seminar examines research and conceptual literature on policies and management practices in providing services and social support for persons with substantial, life-long disabilities; emphasis on research, problems in education, prevention, health care, employment, rehabilitation and related services.

Intervention Strategies for Persons with Developmental Disabilities: Interdisciplinary Perspectives offered winter 1990 will have Scott McConnell as instructor. This course introduces students from education and other human service disciplines to the principles and procedures of interdisciplinary intervention strategies for persons with developmental disabilities. It will also examine relative strength of intra- and interdisciplinary approaches and developmental of skills for collaborating with other professionals to solve important intervention problems in a variety of treatment settings.

These courses may be taken separately or as part of the Institute's Interdisciplinary Studies in Developmental Disabilities certificate program. For more information about the certificate program, call the Institute at (612) 624-4848.

EMPLOYMENT OPPORTUNITIES

Recreation Integration Facilitator

Assist teenagers with developmental disabilities to fully access community leisure service settings. Work with individuals and families on issues of empowerment. Provide technical assistance to service providers. Begin Oct 1. College degree in recreation, special education or related field and knowledge of integration strategies necessary. Full-time one-year position. Send resume to Dorothy Skarnulis, ARC St. Paul, 65 E. Kellogg Blvd., St. Paul, MN 55101. Inquiries to Tip Ray at 612/224-3301.

Project Director

Responsible for conducting two projects--one in creative strategies to develop friendships between individuals with and without disabilities and one to conduct training in Personal Futures Planning in Greater Minnesota. Position will involve supervision, budgeting, management, training, preparation of written materials and working with an advisory council. Minimum BA in special education, vocational rehabilitation, social work and direct experience in community integration activities and training in PASS, Frameworks or Personal Futures Planning. Apply to Dr. Angela Novak Amado, HSRDC, 1195 Juno Ave., St. Paul, MN 55116 or 612/698-5666 or 227-9117.

Community Specialist

Responsible for conducting day-to-day activity of Friends project. Assist with staff training; managing, planning and implementing activities for individuals; contacting community education activities; assist in report and manual preparation. Requirements include two years undergraduate education in field related to people with DD, direct experience in community integration activities, group process skills and training in PASS, Frameworks or Personal Futures Planning. Contact Dr. Novak Amado at the above address and phone.

RECREATION

Cub Scouts Sign-Up

Boys ages 7-11 may join theCub Scouts on Sept. 14 when the Indianhead Council, Boy Scouts of America holds its annual School Night for Scouting. Cub Scouts participate in a variety of activities, work on projects with adults and other boys, and make a lot of friends. Boys with disabilities participate in the same Cub Scout packs as all other boys. Boys should receive an invitation to attend School Night at their local school on Sept. 14. For further information, call Tom Frantzen at the Indianhead Council at 612/224-1891.

New Accessible Recreation Center Open

A new outdoor recreation center and creative play Area recently opened at the Clifton E. French Regional Park in Plymouth. The facilities were designed to be accessible to individuals with disabilities and include a snack bar, outdoor recreation equipment rental, picnic areas, paved bike/hike trails and a large multi-level play area for children of all ages.

WORKSHOP/CONFERENCES

September 11, 1989

"*Letting the Flowers Grow*" is a seminar about helping people with disabilities develop healthy attitudes toward friendship, dating, sexuality and love. The seminar is sponsored by United Cerebral Palsy (UCP) of Minnesota. It will take place from 8:30 a.m. to 5:00 p.m. at the Radisson Hotel University, 615 Washington Av. SE, Minneapolis. Geoffrey Garwick, clinical psychologist, and Claudia Swanson, Ramsey County Human Services supervisor, will be the presenters. Both have extensive experience working with groups of people about sexuality issues. The fees are $6 for people with disabilities, $12 for family members and $30 for human service staff. Send registration to UCP of Minnesota, Suite S-233, 1821 University Av., St. Paul, MN 55101. For further information, call (612) 646-7588.

September 27-30, 1989

The National Association for Rights Protection and Advocacy is sponsoring a conference called "*Closing Ranks, Opening Doors.*" It will be held at the Radisson Hotel St. Paul. Featured speakers will be author Huey Freeman, AIDS rights advocate Don Schmidt, and mental health administrator James W. Stockdill. Conference registration is $125. Over 50 workshop sessions with national speakers will cover topics including case management, getting community services, mental health litigation, psychotropic medication monitoring, social security benefits, independent living, peer advocacy, fair housing act, vulnerable refugees and class action litigation. For further information or a complete program, contact 1989 NAPRA Rights Conference, c/o Mental Health Association of Minnesota, 328 E. Hennepin Av., Minneapolis, MN 55414, or call (612)331-6840.

October 7, 1989

An "*Accessibility Fair,*" organized by the Access Resource Network will be held at the Northland Inn (I-694 and Boone Av.) from 9 a.m. to 5 p.m. Workshops designed for consumers and professionals who deal with handicap accessibility issues will cover topics such as legal requirements, community issues and practical recommendations for the home. In addition, an extensive array of exhibits by area vendors will feature products used for access, recreation and daily living aids. There will also be displays by service providers, referral sources and funding agencies. For further information, contact Shannon McGurran or Coral Shanahan at (612)520-0518.

October 11-12, 1989

The Institute for Disabilities Studies is sponsoring "*Return Us the Children: Prevention and Early Intervention in Developmental Disabilities*" at the Radisson Minnetonka. The fee is $115; scholarships are available. The conference will present current research, clinical and program strategies aimed at preventing developmental disabilities and minimizing their impact on children and families at risk. Major speakers will address issues such a fetal alcohol syndrome, nutrition, children in poverty and early education intervention. For further information, scholarships or a brochure contace Carol Siegel, Professional Development and Conference Services, 107 Armory, University of Minnesota, Minneapolis, MN 55455 or (612) 625-5059.

October 18-20, 1989

"*Preview of the '90s*" is the theme of the 1989 Minnesota Community Integration Conference sponsored by the Minnesota Association of Rehabilitation Facilities, Association of Residential Resources in Minnesota, the Minnesota Developmental Achievement Center Association and Staples Technical college will be held at Madden's Inn in Brainerd. Workshops will focus on the areas of legislation and public policy, case management, administrative and middle management, mental health, motivation, residential and supported employment and vocational. Full conference registration is $100 not including lodging or meals. For registration or further information contact the 1989 Minnesota Community Integration Conference, 1821 University Av., 376-S, St. Paul, MN 55104 or (612) 646-0900.

October 24-25, 1989

New Concepts in Madison, Wis. is sponsoring the fourth annual National Community Integration Forum, "*Perspectives on Empowerment, The Presence of Possibilities,*" at the Concourse Hotel in Madison. This year's conference describes the opportunities that must be present for individuals seeking to have more control over their lives, becoming an integral part of their community and transforming the images into reality. Invited speakers include Gunnar Dybwad, Hank Bersani, Anne M. Donnellan, Colleen Wieck, Barbara Sacket, Herb Lovett and a number of self advocates. Registration is $85. For further information and a registration brochure, contact New Concepts, 2417 Parmenter St., P.O. Box 376, Middleton, WI 53562, or (608) 831-1221.

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Governor's Planning Council on Developmental Disabilities
300 Centennial Office Bldg.
658 Cedar St.
St. Paul, MInnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
(612) 296-4018

SELF-DETERMINATION: MAKING IT HAPPEN

This is a follow-up article to one that appeared in the May 1989 issue of DD Information Exchange--State Supplement, "Variations on a Theme: 'Self-Determination,' What Is It?" (pp. 5-7). That article summarized ideas expressed by self-advocates at "The National Conference on Self-Determination by Persons with Disabilities." The conference was held at the Crystal City Gateway Marriott Hotel, Crystal City, Virginia, January 9-10, 1989. The conference was sponsored by the Office of Special Education and Rehabilitative Services of the U.S. Department of Education in conjunction with the Research and Training Center on Community Living of the University of Minnesota and the Minnesota Governor's Planning Council on Developmental Disabilities.

A summary of the conference proceedings has now been published, entitled National Conference on Self-Determination, edited by Robert Perske. Information about how to obtain this new publication is provided at the end of this article.

The purpose of this article is to share the recommendations made by the conference participants. Perske observed, "Though there were differences, (the self-advocates) were together when they spoke about:

- 'Being pressured toward the margins of society;'
- 'Having folks label us and treat us as if we weren't whole people;' and
- 'Having to go to programs where everyone else makes choices we should be making.'"

The self-advocates recommended:

1. The enabling of people with disabilities to determine their own futures be seen as the top priority in all government policymaking functions.

2. Advocacy organizations should enable persons with disabilities to testify for themselves at formal government hearings.

3. The term "least restrictive environment" (LRE), now appearing in many federal laws and regulations doesn't go far enough.

4. A program for supporting state and local self-advocacy organizations be developed.

5. Grant proposals benefitting persons with disabilities be rated according to how well they include the concept of self-determination.

6. A conference of persons with disabilities be called to evaluate and redirect the Rehabilitative Services Administration.

7. Grant review teams should include persons with disabilities.

8. Internships and study fellowships be created that enable persons with disabilities to work and learn in government agencies.

9 Persons with disabilities (including nonvocal persons via interpreters) be helped to compile their own oral history.

10. A program for reshaping professional attitudes be instituted for those already working in the field.

11. Universities reshape their preservice and in-service training programs to include self-determination as a top priority.

12. School programs enable nondisabled students and those with disabilities to teach each other.

13. Sign language for persons with deafness be taught to nondisabled students in elementary schools and be included as a language course in all secondary public school language departments.

14. A formal course in human disability be included in the social studies department of public schools.

15. Persons with disabilities be provided formal courses

in self-assertion.

16. Help reinforce friendships between students with and without disabilities.

17. People with disabilities be involved in their own program planning sessions.

18 Enable persons with all kinds of disabilities to form a national coalition.

19. People who have been psychiatrically labeled be included in all coalition efforts and be allowed to represent themselves.

20. A series of model programs be funded that exemplify self-determination attitudes and practices.

21. State Protection and Advocacy Agencies hire persons with disabilities as community organizers.

22. Government should enable electronic and print media to highlight the real disability culture--its positive aspects and its soon-to-be developed oral history.

23. Bookstores set up a regular section on disability.

24. Work for universal design in technology.

25. Telecommunication devices for persons with deafness (TDD) have expanded availability and usage, and be more readily identified and understood by all citizens.

26. Innovations benefitting people with disabilities (curb cuts, television captions, accessible voter booths, security guards on subways, etc.) be advertised as helping other citizens as well.

27. Unfair financial support systems continue to be exposed when they limit the self-determination of people with disabilities.

28. Nondisabled persons be helped with the perceived "inner terror" they experience in the presence of those with disabilities.

29. A national research and training center on self-determination be created.

A plea from one of the self-advocates captured the spirit of the conference, "We want our people free. We want them well-supported in the community where they always belonged in the first place."

A free copy of the publication may be obtained from: Institute on Community Integration; 6 Pattee Hall; University of Minnesota; 150 Pillsbury Drive, Southeast; Minneapolis, Minnesota 55455. Tel. (612) 624-4848.

PUBLICATIONS/RESOURCES

List of Self-Advocacy Publications Available: A number of helpful materials are available at no cost or at relatively low prices from People First of Washington. Following are only a few examples:

* Assertiveness: $1.00, 12 pages, a curriculum for teaching the difference between non-assertive, assertive, and aggressive behavior. Includes graphics for non-readers, and skits for practice.

* Officers Handbook: $2.00, 21 pages, provides information on the duties, role, and responsibilities of a good officer. Includes guidelines for setting up an agenda, conducting a meeting, voting on chapter issues and electing officers.

* People First: $4.00, 48 pages, an encompassing look at People First support groups, meetings, workshops, conventions, and core groups.

* People First Newsletter: $5.00 per year for those living outside the state of Washington, published quarterly to keep readers up-to-date about People First.

Other topics include: evaluating programs, renting an apartment, setting goals, successful meetings, voter education, and more. For a complete listing, contact: People First of Washington; P.O. Box 381; Tacoma, Washington 98401. Tel. (206) 272-2811.

Policy Analysis Paper No. 26: Supported Employment: Review of the Literature. (1989, March 31). The purpose of this paper was to briefly summarize a review of the literature on supported employment. Four common features were identified among several definitions of supported employment: a) it takes place in nonsegregated settings; b) it involves meaningful work; c) it requires ongoing support and services for maintaining employment; and d) it allows opportunities to socially interact with individuals without disabilities. Several approaches to providing supported employment were described and analyzed: individual job placements, enclave, mobile crew, and benchwork. An extensive comparison of the organizational and procedural characteristics between these models were analyzed by Mank, Rhodes, and Bellamy (1986). Barriers identified in providing supported employment were attitudes, job performance, cost, unstable funding mechanisms, reduction in benefits, and availability of jobs. Barriers could be overcome by providing: strong family and advocacy support; outcome oriented services which foster independence, productivity, and integration into the community; a restructuring of resources to meet costs; support to federal initiatives to remove disincentives; and aggressive and creative encounters with community members to bring about employment options. Successful approaches were outlined by Bellamy (1987): a) focus on tangible outcomes; b) build slowly on strengths; c) maintain a clear employment strategy; and d) plan for competition between business and service needs.

Copies of this publication have already been mailed to those on the Policy Analysis Series mailing list. To receive a copy, contact: Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. Tel. (612) 296-4018, or (612) 296-9962 (TDD).

CONFERENCES/WORKSHOPS

September 20, 21, and 22, 1989

"*Supported Employment for People Challenged by Deaf-Blindness: The Keys to Success*" is the title of a conference that will be held at the Sunwood Inn in Bandana Square, St. Paul, MN. The conference will be sponsored by Project Employment of In-Touch, Inc., and the Minnesota State Services for the Blind (SSB). Topics will include: communication, assessment, job coaching, and team building. For more information, contact: (a) Jerry Wood, In-Touch, Inc., (612) 342-2066 (voice and TDD); or (b) Linda Lingen, SSB, (612) 642- 0506 (TDD).

September 28-29, 1989

"*Exploring Substitute Decision Making: Getting to Know Minnesota*" is the theme of the First Annual State Conference of the Minnesota Association for Guardianship and Conservatorship. The conference will be held at the Ambassador Hotel in St. Louis Park. Topics will include: medical ethics, legal issues, and guardianship models. Practical assistance will be offered through mock hearings on how to handle difficult situations. Contact: Kay C. Hendrikson, Minnesota Department of Human Services, (612) 296-3618.

October 5-7, 1989

The Association for Retarded Citizens of the United States will hold its 40th Annual National Convention at the San Antonio Convention Center and Marriott Riverwalk Hotel in San Antonio, Texas. The theme is "*The Challenge of Change--Choices for the 90's.*" For more information, contact: ARC/US; National Headquarters; 2501 Avenue "J"; Arlington, Texas 76006. Tel. (817) 640-0204.

October 19-20, 1989

"*Integrated Education: Realizing the Vision*" is a national conference designed to provide information on strategies and program models which have been effective in planning, delivering, and evaluating quality integrated education programs for individuals with severe disabilities. Keynote address will be presented by Marsha Forest, Director of Education at Frontier College and Director of the Centre for Integrated Education. Other speakers will include: Tom Gilhool, George Flynn, Barbara Buswell, Jeffrey Strully, Susan Stainback, William Stainback, Robi Kronberg, Terri Rogers-Connolly, Richard Schattman, Douglas Biklen, Sharon Freagon, Bill Peters, Alison Ford, Luanna Meyer, Jacqueline Thousand, Linda Kjerland, Diane Gerads-Schmidt, Judy Neis and Jean Mendenhall. The conference will be held at the Scanticon-Minneapolis Conference Center in Plymouth. For additional information, contact: Integrated Education Conference; Institute on Community Integration; 101 Pattee Hall; 150 Pillsbury Drive, Southeast; Minneapolis, MN 55455. Tel. (612) 625-3061.

October 24, 1989, Rochester Community College

Frederick T. Dearborn from the Office of Civil Rights of the U.S. Department of Education will present at two workshop sessions: 1:00 p.m. and 7:00 p.m. at the Coffman Room, Rochester Community College in Rochester, Minnesota. Dearborn is Technical Assistance Coordinator of the Postsecondary Education Division in Region V Office in Chicago. He will discuss the implications and experiences of implementing Section 504 of the Rehabilitation Act of 1973--particularly how policies and practices can provide accessibility to students with disabilities in postsecondary educational settings. Contact: Bonnie Mercer; Rochester Community College; 851 30th Avenue, Southeast; Rochester, Minnesota 55904-4999. Tel. (507) 285-7210.

October 24-28, 1989

"*Microcomputer Technology in Special Education and Rehabilitation,*" is the Seventh Annual Conference sponsored by Closing the Gap, Inc. It will be held at the Radisson South Hotel in Minneapolis. Nineteen preconference workshops will be held on October 24 and 25 to provide in-depth training in the professional skills necessary to successfully implement microcomputer technology into the curriculum for students with disabilities. On October 26 through 28 there will be over 100 sessions describing and/or demonstrating successful applications of computer technology for persons with disabilities. For more information, contact: Closing the Gap, Inc.; P.O. Box 68; Henderson, MN. Tel. (612) 248-3294.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

LENDING LIBRARY SELECTIONS

The following videotapes are available on loan:

Awareness Training: Stereotypes and Prejudices Affecting the Handicapped Employee (37 minutes), Doe West: Commissioner for Handicapped Affairs, Defense Logistics Agency, City of Boston.

E.E.O. Counseling Update: The Handicapped Program (Handicapped Awareness) (27 minutes), Doe West: Commissioner for Handicapped Affairs, Defense Logistics Agency, City of Boston.

An Interview with Herb Lovett, Minnesota Governor's Planning Council on Developmental Disabilities.

Jenny's Story: Integration Action Group (15:27 minutes), Richmond Hill, Ontario, Canada, 1988.

A New Horizon, Association for Retarded Citizens of the United States.

Partnership for Quality Services (24 minutes), Association for Retarded Citizens of Minnesota.

Peer Tutoring: Children Helping Children (22:45 minutes), Colorado Developmental Disabilities Council.

Planning for Independence: Legal Alternatives to Conservatorship for Developmentally Disabled Adults (45 minutes), Guardianship Diversion Project, Center for Public Interest Television, Hollywood, California.

Richard and Donna, Minnesota Supported Employment Project, Department of Jobs and Training.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

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If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street, St. Paul, MN 55101

(TIME-DATED MATERIAL)

D D INFORMATION EXCHANGE

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REALIZING THE VISION ACCOMPLISHMENT

The Age of Technology

The computer can be the great communicator. In particular, the computer can reduce learning barriers for persons with physical disabilities. Norman Coombs, who is Professor of History at Rochester Institute of Technology in Rochester, NY, is totally blind. He uses a microcomputer with a speech synthesizer to interface with the college's mainframe and to communicate through electronic mail and computer conferencing with his students, even with hearing impaired students without the intervention of an interpreter.

Traditionally Coombs has used interpreters in class and also in his office appointments with students. Meshing three schedules, however, was difficult at best. Since he began using a computer and speech synthesizer, he has students come to his office alone, and they take turns at the computer keyboard. When the deaf student types, the synthesizer "talks"; and when he types, the deaf student can read the screen. Both participants like the more direct and immediate contact.

Another advance came when Coombs was able to connect his microcomputer to the institute's mainframe and access electronic mail. In the past, when students would turn in term papers, he would pay a reader to read them to him. Now the students send their papers electronically and the computer reads for free. He particularly like this method because the computer can work day or night, does not need breaks and does not offer its own opinions of what it's reading.

One of his first students who submitted work to him in this way was a hearing-impaired woman. After he replied to her, she wrote back excitedly, saying that this was the first time in her life that she had talked: with a professor without an interpreter. More exciting was that the professor was blind and that the computer had transcended a double communication barrier in one leap.

When the college wanted to improve the delivery of its telecourses, Coombs was the first to venture into this field. After a conference system was purchased for the mainframe, the college purchased modems to loan to students who had microcomputers. He taught the information-gathering portion of the course through broadcast videos and textbook readings as in a traditional telecourse. However the electronic mail part of the system substituted for phone and office visits and was found to be very efficient. The computer conference capability added a new dimension normally absent from regular telecourses. The telecourse students like the close, regular contact with their professor, and they achieved a higher course average than did the classroom students.

Several hearing-impaired students have also taken this telecourse with the videos being captioned. It totally obviated the need for an interpreter. This seemed particularly beneficial to students who had lost their hearing as young adults and were not fluent in sign language. Besides the advantage of learning from computer conference discussion from captioned videos, they also were able to join in computer conference discussion like anyone else, making their hearing impairment and Coombs' blindness invisible and irrelevant.

[The information for this article was adapted from "The Computer as the Great Communicator" in T.H.E. JOURNAL]

NEW APPOINTMENTS MADE TO DEVELOPMENTAL DISABILITIES ADVISORY COMMITTEE

On September 28, 1989 the Metropolitan Council made appointments to the Developmental Disabilities Advisory Committee. The new terms are effective October 1. The following people were appointed.

Linda Rother, Eagan, consumer reappointment. Linda is serving her second year as Chair of the DD Advisory Committee.

Gary Ellis, Shoreview, consumer

Gerald Glomb, Roseville, provider reappointment

David Hancox, Golden Valley, provider

Paula Reeves, Lakeville, consumer, reappointment

Barbara J Schultz, St. Paul, consumer

Sue D. Swenson, Minneapolis, consumer

Michelle R. Veith, Eden Prairie, consumer

Laura Weber, St. Paul, provider

William Zuber, Roseville, provider

The DD Advisory Committee consits of 25 members and is made up of at least 50 percent consumers. For 1990 there are 14 consumer and 11 providers. The DD Advisory Committee discusses issues related to developmental disabilities and advises the Metropolitan Council on matters which the Council should make policy decisions. 34 applications were received for the nine available openings.

FOR YOUR INFORMATION

Resources and Reports on Community Integration and Family Supports

The Center on Human Policy, through its Research and Training Center on Community Integration, has developed a variety of reports and resources on the integration of people with severe disabilities into community life and family supports. These reports are available at the cost of reproduction and postage. Regarding family supports, for example, resources include: an annotated bibliography; Family Support Services Newsbulletin (1987); an article form Exceptional Children on permanency planning for children and youth; and reports resulting from site visits to exemplary programs throughout the United States. To receive a listing of resources on family supports and a complete publication list with order forms, contact: Center on Human Policy; Syracuse University; 200 Huntington Hall; Syracuse, NY 13244-2340. Tel. (315) 443-3851.

National Directory of Organizations Serving Parents of Children and Youth with Emotional and Behavioral Disorders

1989, Portland State University. Price: $8.00. This is the second edition lists 344 U.S. organizations providing the following types of services: education and information, parent training, case and systems level advocacy, support groups, and direct assistance such as respite care, transportation, and child care. Contact: Research and Training Center; Regional Research Institute of Human Services; Portland State University; P.O. Box 751; Portland Oregon 97207-0751. Tel. (503) 464-4040.

Videotapes on Sexuality and Siblings Issues

Two new videotapes of workshops have been produced by Parent Advocacy Coalition for Educational Rights (PACER). The tapes look at the challenges faced by a parent who must deal with the sexuality of a growing child with disabilities and the challenges faced by a young person who grows up with a brother or sister who has a disability. Betty Pendler, a nationally-known speaker on sexuality of children with disabilities speaks on one of the videotapes. On the other, four young people speak about their experiences of growing up with a sibling who has a physical or emotional disability. These tapes are available for rent ($10) or purchase ($25) from PACER Center, 4826 Chicago Av. S., Minneapolis, MN 55417.

Just Enough to Know Better

The National Braille Press Inc., offers a Braille primer for sighted parents. The self-paced workbook allows parents to use their sight to learn to identify the Braille alphabet, numbers, contractions and some rule exceptions. It is written for parents who want to help their son or daughter, who is blind, learn to read. The workbook is $12.50 and can be ordered form National Braille Press Inc., 88 S. Stephen St., Boston, MA 02115.

Special Buddies in the Parks

"Special Buddies" is a set of four videotapes which is designed to help children in grades two to six better understand learning disabilities, speech and language problems, developmental delays and emotional and behavior problems. The set of tapes cost $130 and is available from the Special Services Office, City of Bloomington, 2215 W. Old Shakopee Rd., Bloomington, MN 55431. (612) 887-9604 ext 409.

Exploring the World through Play

A new booklet about play has ben developed. It explores the use of mastery behaviors by young children with developmental delays. It is available for $2 from Susan Hupp, Ph.D, Institute for Disabilities Studies, University of Minnesota, Minneapolis, MN 55455.

Behavior Managment Training Materials Available

The Institute on Community Integration at the University of Minnesota has produced a resource guide that reviews available staff training materials in the area of behavior management. The guide, *"Behaior Management for Direct Care Staff Serving Persons with Developmental Disabilities: A Review of Inservice Training Materials,"* is intended to assist in the acquisition of quality training materials by program directors, training coordinators, and other supervisory personnel in group home, vocational or preservice settings. The guide review 20 different resources, addressing the types of topics covered by the materials, the intended audiences, strengths and weaknesses of the materials, costs, and sources. Copies of the guide are $3 and may be ordered by sending a check payable to Univeristy of Minnesota to: Institute on Community Integration, 109 Pattee Hall, University of Minnesota, 150 Pillsbury Dr. S.E., Minneapolis, MN 55455.

CONFERENCES/WORKSHOPS

October 16-17, 1989

Experience and learn concepts and skills for support group leadership at *"Support Group Facilitator Training."* A variety of approaches will be used to teach effective helping in a group, facilitation of the group sessions and planning and organizing of mutual help groups. Previous group leadership experience not necessary for this training. The training will be held 8:30 a.m. to 4:30 p.m. at St. Timothy's Lutheran Church, 886 W. Nevada Av., St. Paul. The fee is $95. For more information contact: Wilder Foundation, Community Care Resources at 612/642-4060

October 18-20, 1989

"Minnesota Community Integration Conference: Preview of the '90s" will be held at Madden's Inn on Gull Lake, Brainerd. The Conference is co-sponsored by the Minnesota Association of Rehabilitation Facilities (MARF), the Association of Residential Resources in Minnesota (ARRM), the Minnesota Developmental Achievement Center Association (MnDACA) and the Staples Technical College. Contact: 1989 Minnesota Community Integration Conference, 1821 University Av., #277--S; St. Paul, MN 55104.

October 20, 1989

The Minnesota Speech-Language-Hearing Association will hold its Fall Meeting *"Role Modifications: Challenge of the '90s"* at the Sheraton Park Place Hotel, 5555 Wayzata Boulevard, Minneapolis, MN. Jerry Northern, Denver, Colorado, will speak about the chronic middle ear problems of children. Contact: Jack Lindgren; Bloomington Schools; Independent School Dist. 271; 9800 Portland Av. S., Bloomington, MN 55420.

October 21-25, 1989

"Crossing the Boundaries: Confronting the Future" is the title of the 5th Annual International Early Childhood Conference on Children with Special Needs. The Minnesota Council for Exceptional Children has been chosen to host the conference which will be held at the Marriott Hotel at City Center in Minneapolis. The international conference will bring together over one thousand persons from varied disciplines to share skills and information concerning young children with special needs. The conference runs for days and includes 12 all-day workshops, nearly 100 concurrent sessions, 6 half-day workshops, social events and professional meetings. For registration information: Barbara J. Smith or Kathleen Edwards, Early Childhood Intervention Program, University of Pittsburgh, 3811 O'Hara St., Pittsburgh, PA 15213. (412) 624-2012.

October 23, 1989

"Working Positively with Special Educators" is part of a

family forum series offered by ARC Hennepin. Speaker, Barbara Gill, will offer ideas on obtaining the best possible special education services for children plus collaboration and negotiation skills for parents. The forum will be held from 7 to 8:45 p.m. at the Southdale Hennepin Area Library, Ethel Berry Room, 7001 York Av., Edina. The fee is $5 for ARC members and $10 for non members.

October 24 & 25, 1989

"*Perspectives on Empowerment: The Presence of Possibilities*" is the theme of the Fourth Annual National Community Integration Forum, Concourse Hotel, Madison, Wisconsin. Contact: New Concepts; 2417 Parmenter Street; P.O. Box 376; Middleton, WI 53562.

November 3, 1989

Minneapolis Children's Hospital is sponsoring "*Born at Risk: The Early Years After the Neonatal Intensive Care Experience*" a conference for both parents and professionals. Heide Depue, psychologist with the Good Beginnings Program at Minneapolis Children's Medical Center, and Lynne Frigaard, director for the Pilot Parent Minnesota will be the keynote speakers at the event. The conference will be at the Minneapolis Metrodome Hilton from 8:15 a.m. to 4:30 p.m. Registration fees are $45 for professionals and $30 for parents. Lunch, breaks and materials are included. Call (612) 863-5820 by Mon., Oct 23 to register.

November 3-4, 1989

The Minnesota Association for Children and Adults with Learning Disabilities Annual Conference is titled "*Working to Learn and Learning to Work.*" It will be held at the Airport Hilton Hotel in Bloomington. Melvin D. Levine, M.D., Professor of Pediatrics at the University of North Carolina will be the keynote speaker. Workshop topics include mainstreaming, postsecondary access and accommodations, intervention, chemical dependency and others. For further information, write to: Minnesota ACLD, 1821University Av., Ste. 494-N, St. Paul, MN 55104, or call (612) 646-6136.

November 10-11, 1989

The 35th Annual Conference of the Epilepsy Foundation of Minnesota, "*Looking to the Future,*" will be held at the Normandy Inn in Minneapolis. Contact: John Thompson; Epilepsy Foundation of Minnesota; 672 Transfer Road; St. Paul, MN 55114. Tel. (612) 646-8675, or (800) 292-7932.

FUTURE EVENT

MARCH 2-5, 1990

The National Parent to Parent Conference, "*Toward New Horizons,*" will be held at the Sheraton Grand Hotel in Tampa, Florida. Co-sponsors include Parent to Parent of Florida and the Beach Center on Families and Disability at the University of Kansas. Contact Parent to Parent of Florida, 3500 East Fletcher Av., Suite 225, Tampa, Florida 33613.

EMPLOYMENT OPPORTUNITIES

Part-time Employment Specialist

Train and supervise a person with challenging behaviors, brittle diabetes and mental retardation in making wood products. Carpentry or woodworking skills needed. Training will be provided. Must be willing to use own vehicle. Part-time 10 a.m. to noon Monday through Friday. West St. Paul location. Starting pay is $7.50/hr. Send resume to: Kaposia Inc., 380 E. Lafayette Freeway S., St. Paul, MN 55107-1216.

Program Coordinator

Full-time position for Qualified Mental Retardation Professional with background in Minnesota mental retardation/mental illness programs. Responsible for overall operation of branch facility including client programs, staff supervision, building and vehicle maintenance, community supported work and public relations. Salary negotiable based on experience. Excellent benefits including employer paid pension and health, dental, and life insurance. EOE. Send resume to Frederic Hoffman, Director, Mille Lacs County DAC, Inc., PO Box 92, Milaca, MN 56353.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
October 1989

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300 Centennial Office Bldg.
658 Cedar St.
St. Paul, MInnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
(612) 296-4018

ROLE OF PRIMARY CARE PHYSICIAN CRITICAL TO IMPLEMENTATION OF P.L. 99-457

The American Academy of Pediatrics (AAP) has recently published *Proceedings from a National Conference on Public Law 99-457: Physician Participation in the Implementation of the Law.* This National Conference was held in cooperation with the federal Bureau of Maternal and Child Health and Resources Development on November 19-21, 1988, in Washington, DC. The need for collaboration between pediatrician and families has intensified due to the passage of Part H of the Education of All Handicapped Children Act of 1986 (P.L. 99-457), which extended education services to children with disabilities from birth to 36 months of age.

The intent of the Conference was to increase opportunities for pediatricians to provide timely and effective medical and health services, to work cooperatively with parents and professionals who provide those services, and to cooperatively plan local, regional, and statewide early intervention services. The conference was designed to draw upon the expertise of invited participants to identify and agree upon those activities leading to full primary care physician participation in the implementation of P.L. 99-457.

Two spheres of influence were addressed--the clinical level (involvement with children and families) and the systemic level (influencing the system, such as participation in communities, networking with other professionals and parent groups, and involvement in public information efforts). Output from group sessions resulted in listing a sequence of activities for physician participation as well as strategies for enhancing physician/lead agency interactions. The sequence of activities resulted in the determination of competencies required by physicians electing to participate in child find, assessment, and Individualized Family Service Plan activities.

At the policy level, several recommendations were made to enhance interactions between AAP and the Lead Agency (e.g. in Minnesota the Lead Agency is the Department of Education). AAP Chapter responsibilities should (a) assume a strong child advocacy position and lobby state legislators; and
(b) work to support the Lead Agency's efforts in the political arena. Joint responsibilities identified were:

- Ensure. AAP representation on each Interagency Coordinating Council;
- Enhance positive interactions between primary care physicians and professionals from other disciplines;
- Improve state and private reimbursement for services;
- Develop uniform standards for services;
- Develop simple, clear, and flexible regulations to ensure access to services;
- Develop mechanisms to ensure the continuous flow of important information between both parties;
- Develop jointly sponsored training initiatives for primary care physicians;
- Create and distribute professional education materials relating to the importance of early identification, and effectiveness of intervention programs;
- Improve awareness of families about available programs and referral sources;
- Explore mechanisms leading to the utilization of less pejorative labels (or no labels at all) to reduce the stigma often associated with having to conform to various eligibility criteria;
- Ensure that the child find system will be: family centered; highly sensitive; tiered to achieve greater specificity in subsequent phases; and focused on both the manifest delay and at-risk populations;
- Ensure that the child find system will include: appropriate risk registries; public information and awareness activities; easy access to sources of screening (genetic, developmental, etc.); understandable interpretation of findings to families; opportunities for family involvement in decision

making on several levels; close linkage with sources of assessment; communication and coordination of all elements; and adequate funding and personnel.

* Most conference participants agreed that broad-based information dissemination was essential to the task of informing and involving primary care physicians in state-level implementation. Specific strategies must be developed to enhance information exchange between physicians, families, other professionals, and state and local agencies, such as: distribute AAP position statements as guides; and provide models for validated approaches regarding screening, assessment, development of Individualized Family Service Plans, and at-risk registries.

For information about the *Conference Proceedings*, write: American Academy of Pediatrics; Division of Child and Adolescent Health; 141 Northwest Point Blvd.; P.O. Box 927; Elk Grove Village, IL 60009-0927.

GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES SEEKS NEW MEMBERS

Applications are being accepted to fill anticipated vacancies on the Governor's Planning Council on Developmental Disabilities. Those appointed by the Governor will begin serving on the Council in February 1990.

The Council assists in the selection of priorities for the development of a state plan. The Council also advises the Governor of Minnesota on policies pertaining to the provision of an array of services to people with developmental disabilities and their families.

People with "developmental disabilities" are those who have severe, chronic physical or mental disabilities, which appear before age twenty-two and are likely to continue indefinitely. A developmental disability significantly limits three or more major life activities, such as: self-care, language, learning, mobility, self-direction, independent living, and economic self-sufficiency.

Persons who have a developmental disability and those who represent the general public interest are encouraged to apply.

To apply, please contact the Office of the Secretary of State to request the form entitled "Application for Service in State Agency." Address: State Office Building, Room 180, St. Paul, Minnesota 55155. Telephone: (612) 296-2805.

Applications are to be filed at the Office of the Secretary of State by December 1, 1989.

FEDERAL/STATE PARTNERSHIP FORMED ON WORK INCENTIVES

On August 16, 1989, Marlene M. Moleski, Regional Commissioner for the Chicago Region of the Social Security Administration and William Niederloh, Assistant Commissioner, Minnesota Division of Rehabilitation Services signed an agreement designed to improve access to work incentives for Minnesotans with disabilities receiving Supplemental Security Income (SSI). The agreement provides for improved cooperation between the state and federal government in identifying individuals who could benefit from one of the requirements under the SSI program--to establish Plans for Achieving Self-Support (PASS).

Such plans allow persons with disabilities who qualify for or currently receive SSI to set aside income and/or resources needed to achieve an occupational objective such as education, vocational training, or a business. The exclusion of certain income and resources under a PASS can help the individual establish or maintain eligibility and maintain or increase payment amount. It can make the difference in the individual's attempt to achieve economic independence.

For more information about PASS or other work incentive provisions, call the Social Security Administration toll free at: 1 (800) 234-5SSA.

COMMUNITY SERVICE TRAINING PROGRAM OFFERED AT THE INSTITUTE ON COMMUNITY INTEGRATION

A community service and career exploration program has been developed at the Institute on Community Integration at the University of Minnesota. The program is designed to provide opportunities for undergraduate and graduate students to gain training and supervised experience by: (a) working directly with individuals with developmental disabilities;
(b) participating in community research projects; or
(c) contributing to the work of community organizations that provide services to persons with developmental disabilities.

Students may participate as volunteers or may elect to enroll for academic credit. All students will participate in a series of seminars that will be conducted by nationally recognized faculty members from a variety of departments at the University. After training, two options are available: (a) students may be matched with an individual with developmental disabilities to serve as support persons or companions; and (b) students may become involved in one of many community research and demonstration projects underway at the University.

Contact: Coordinator, Community Service Training Program; Institute on Community Integration; Department of Educational Psychology; Room 6 Pattee Hall; 150 Pillsbury Drive, SE; Minneapolis, MN 55455. Tel. (612) 624-6300.

PUBLICATIONS/RESOURCES

Chemical Dependency Assessment/Screening Tools and Training Materials--The Hazelden Foundation has developed several resources regarding chemical dependency. The information is intended to assist professionals working with persons with physical or mental disabilities and persons who are elderly. The following products were developed under a one-year research and training grant from the Chemical Dependency Program Division of the Department of Human Services:

(a) Literature reviews on screening for chemical abuse by persons with physical or mental disabilities, and persons who are elderly;

(b) Screening tools;

(c) Training videotapes on the use of screening tools; and

(d) A Minnesota directory of chemical health services for persons with disabilities and persons who are elderly.

To receive information regarding this project, contact: Sharon Johnson; Chemical Dependency Program Division; Human Services Building; 444 Lafayette Road; St. Paul, MN 55155-3823.

Policy Analysis Paper No. 27: Supported Employment: Review of Grant Recipients and 1986 DAC Data. **(1989,** March 31). As a sequel to Policy Analysis Paper No. 26 (see *Information Exchange--State Supplement*, September 1989, p. 7), which contained a review of the literature about supported employment, this paper reported data about community-based employment for persons with developmental disabilities in Minnesota. Information was collected and analyzed regarding:
1) the results of a three-year grant program on supported employment, which was a priority activity of the Governor's Planning Council on Developmental Disabilities from 1984 through 1986; and 2) the results of a survey of the Minnesota day training and habilitation centers in 1986.

In 1984, there were five grants awarded with 113 persons placed into community-based jobs (i.e., work performed outside of traditional day settings). In 1985, the number of grants increased to nine with 266 people placed. The number of grants increased to 12 in 1986, with 469 community-based work placements. The total earnings in 1985 by 206 individuals was $66,230.66, or $321.50 per individual. In 1986, the total earnings by 355 workers amounted to $369,394.33, or $1,040.54 per person. The leading type of work was maintenance, janitorial, custodian, and/or cleaning.

The 1986 survey of the 82 day training and habilitation centers revealed that 64 centers had at least one person engaged in community-based employment. Fourteen of the centers were providing "supported employment," according to the federal definition. Of the 3,783 persons being served by day training and habilitation centers, 799 were engaged in community-based employment, 50 of whom met the definition of supported employment. During the last quarter of 1986, these individuals worked a total of 58,116 hours, generating over $121,136 in earnings. Also, 544 (68 percent) were in integrated settings. The two leading types of activities worked by persons from day training and habilitation centers were general cleaning/custodial and outdoor seasonal activities. Considerable differences were noted between programs located in the Twin Cities and nonmetropolitan programs: workers in nonmetropolitan areas were more likely to spend more time working within the day habilitation and training center. In the nonmetropolitan settings, the individuals worked fewer hours in community-based settings; jobs which were most likely to involve cleaning, janitorial, and seasonal work.

Copies of this publication have already been mailed to those on the ***Policy Analysis Series*** mailing list. To receive a copy, contact: Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. Tel. (612) 296-4018, or (612) 296-9962 (TDD).

CONFERENCE

October 19-20, 1989

"Integrated Education: Realizing the Vision" is a national conference designed to provide information on strategies and program models which have been effective in planning, delivering, and evaluating quality integrated education programs for individuals with severe disabilities. Keynote address will be presented by Marsha Forest, Director of Education at Frontier College and Director of the Centre for Integrated Education. The conference will be held at the Scanticon-Minneapolis Conference Center in Plymouth. For additional information, contact: Integrated Education Conference; Institute on Community Integration; 101 Pattee Hall; 150 Pillsbury Drive, Southeast; Minneapolis, MN 55455. Tel. (612) 625-3061.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

LENDING LIBRARY SELECTIONS

The following videotapes are available on loan:

Videotape Series: Selections from an ***Oral History of Policy and Advocacy in Developmental Disabilities as Reflected in the Lives and Works of Elizabeth M. Boggs, Gunnar Dybwad, and Rosemary F. Dybwad.*** This ten-volume series was developed by the University Affiliated Program, University of Medicine and Dentistry of New Jersey; and the Robert Wood Johnson Medical School, with funding from the Administration on Developmental Disabilities, Office of Human Development Services. The videotapes include:

Elizabeth M. Boggs, Ph.D.:

--*The Evolution of Public Policy Towards People with Developmental Disabilities: A Half Century Perspective;*

--*The Evolution of the Developmental Disabilities Legislation,* Parts I, II, & III (3 tapes, respectively); and

--*The Social Security Act and Mental Retardation,* Parts I, II, & III (3 tapes, respectively);

Rosemary F. Dybwad, Ph.D.:

--*Normalization and Self-Advocacy;* and

--*The Parent-to-Parent Movement and the Development of the International League of Societies for Persons with Mental Handicaps;*

Gunnar Dywad, Ph.D.:

-- *The Role of the Courts in the Renewal of the Field of Mental Retardation; and*

-- *The Pioneering Role of the National Association for Retarded Citizens.*

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

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INFORMATION EXCHANGE

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November 1989

REALIZING THE VISION THE CHALLENGE OF INDEPENDENCE

Over dinner on a recent evening, Dale informed me that he's "an out-front person." Having no idea what that is, I asked Dale to explain. Dale works at Target Southdale in Edina. As an out-front person he greets people as they enter the store and assists them or directs them to the correct department or isle to find what they came to purchase.

Dale has been working for Target for a couple years now. When he first started, he worked part-time in a non-paid internship for nine weeks. Dale proved he could do the job and was hired on a full-time basis. Dale was an out-front person for one and a half years and was recently appointed to a Level Three, which means he is now a supervisor with three people under him. All the regulars at Target know Dale and greet him upon entering the store. Kids also make a point of coming over to Dale and saying, "Hi."

During the time he has worked for Target, Dale has received the Spirit Award twice. It is an award voted on by managers on a monthly basis and given to an outstanding employee. The award is one day of paid time off. Dale was given the award because of the enthusiasm he exhibits in the job and because people appreciate the job he does. Target also has a Care Club to which customers may write to comment on a particular employee. Dale has received numerous such letter from people describing how helpful he was to them and that he always has a smile on his face. As a result, the president of Target wrote him a note saying "Thanks for making Target a fast, fun, friendly place to shop" (their new slogan).

Dale claims he's coming very close to reaching his life goals. It's taken a long time and he's pleased with what he's doing. Dale was born prematurely to a farming family in a southwestern town of 350 people. There were three boys and one girl in his family. His parents knew quite early in life that he had cerebral palsy and would not function in life as their other children. Wanting to do everything they could for Dale, they took him to several clinics for evaluations and tried Doman-Delicotto for a couple years. Doctors performed knee surgery on his knee cords so they wouldn't bend. His parents were overprotective of him, not wanting him to be hurt. Friends developed over the years were usually children of his parents friends.

Dale attended first grade in his home community. He used a wheel chair to go to school. After first grade, the school told his parents that they "couldn't provide an adequate education" for Dale. The only alternative was a residential school for children with physical handicaps where he attended until he graduated in 1982. Because of distance, Dale only went home to see his family once a month or on major holidays.

The residential school had the dormitory upstairs and the school downstairs. While it was a public school, the students did not participate with their peers in the other public schools in town in activities like homecoming, clubs, or sports. Church was mandatory unless you were sick and their trips to town were to see travelogues. Dale cried for tow days when he went to the school. It wasn't until he was a teenager that he realized he was not a grade level in his academics. His graduating class was the first to receive real diplomas.

At school Dale felt cheated. He felt there had to be more to life than what he was experiencing. At school other people made all the rules. He wanted to begin to make some of his own. He wanted to get an apartment after school, find a job and do what everyone else his age was doing. Someone from Courage Center spoke to the students and described their independence training programs. The next time Dale went home, he told his parents he was moving to the cities, taking the training at Courage and going to live on his own. And that is what he did.

Dale's real interest in employment had always been retail management. Friends who knew him told him he had the personality for it and were positive he could get a job. But after a Division of Vocational Rehabilitation evaluation he was told to go to a sheltered workshop. Dale told them, "No way!" After a brief and successful stint selling light bulbs, he went into a vo-tech retail management program. Much of the training involved running a store on the campus. When the instructor left, The asked Dale to manage the store which he did for seven months. At an open house at the school, a DVR person mentioned a special placement person who later worked with Dale to help him find the job at Target.

Today Dale lives in his own apartment in Bloomington with a personal care attendant and gets around using a power wheel chair and Metro Mobility. He is active in his church where he chairs a committee and people commend him for the effect he has on others in the church because of his positive attitude. Dale is a member of the Optimist Club in Bloomington and the Peer Council of the Metro Center for Independent Living. Recently he was a participant in a videotape at the vo-tech to help instructors include people with disabilities in their classes by increasing their awareness of people with disabilities and their successes on various jobs.

Dales dreams for his future include owning his own business or managing someone else's and having his own van with hand held controls. He's recently been tested for the feasibility of driving. Dale is definitely an "out front" person in many ways.

RESEARCH IN NON-AVERSIVE TREATMENT

Extensive research is showing that non-aversive intervention with people does indeed extinguish negative behaviors, and the resulting improved behaviors can be maintained and generalized in a variety of community environments. With increasing frequency, professionals are asking themselves a question central to themselves, a question central to determining the quality of life for individuals with severe developmental disabilities or excess behaviors: Can society sanction the use of punishments such as electric shock with individuals having severe disabilities which it would not tolerate for use with people without disabilities? An ever-increasing number of professionals believe that society cannot continue to tolerate the use of aversive techniques and, at the same time, have as its goal the integration of individuals with severe disabilities into the total fabric of community life. These professionals believe that, if deinstitutionalization is ultimately to be viewed as having a positive impact, society must do its part to ensure that individuals with severe developmental disabilities and negative behaviors are accepted as full-fledged contributors to community life.

The University of Oregon is in the middle of a five-year grant from the Office of Special Education and Rehabilitative Services (OSERS) to develop, evaluate and disseminate a practical technology of behavior management that is: effective with severe behavior problems; consistent with community standards for non-aversiveness; consistent with the existing science of human behavior; and suitable for use by staff in typical school and community settings. One of the services provided by the University of Oregon is state inservice training to professionals on non-aversive behavior management. Minnesota is one of the states receiving this training. For further information on current and future activities and services of the Research and Training Center at the University of Oregon contact: Robert Horner, Ph.D., Director, Research and Training Center on Community-Referenced Non-Aversive Behavior Management, University of Oregon, 135 Education Building, Eugene, OR 97403.

FOR YOUR INFORMATION

The Crisis Respite Service is a new service recently begun by Alternatives for People with Autism, Inc. The service was developed in response to some gaps that Alternatives felt existed in the service system. The purpose of the service is to provide respite care which is a community-based alternative to emergency institutional placement. It is an interim placement option while another long-term placement is developed for people with autism. To date two individuals have utilized the service. For further information on the service contact Scott A. TenNapel, Director, Habilitation Network, 5624 73rd Av. N., Brooklyn Park, MN 55429 or (612) 561-0330.

PUBLICATIONS

"Everybody Wins! Tips for Supervising the Employee with Mental Retardation" is the title of a new video tape and training manual available from the Association for Retarded Citizens/US. The 11-minute video and seven-page handbook are designed to teach supervisors a variety of effective training techniques. Among the techniques described are demonstration, task breakdown, the use of simple, brief language, routine setting, effective communication and the provision of feedback. The handbook ($1.75) and video ($23) are available from all ARC National Employment and Training Programs or from: ARC National Headquarters, P.O. Box 6109, Arlington, TX 76005. (817) 640-0204.

Living Environments and Mental Retardation is a new book that investigates the effects of living environments on the behavior and emotional patterns of people with mental retardation and their caretakers. It presents information on individuals with all levels of mental retardation, of all ages, living in all types of "homes" from large public institutions to natural and foster families and on their movement between various living arrangements. The volume, edited by Sharon Landesman and Peter Vietze, features contributions by a variety of experts in the developmental disabilities field. It is available for $35 from: American Association on Mental Retardation (AAMR), 1719 Kalorama Road NW, Washington, DC 20009. 1-800-424-3688.

The Accessibility Book: A Building Code Summary and Products Directory is a culmination of recommended products and a reference source for persons designing barrier free installations. Its intention is to assist individuals in the selection of products while also increasing a person's overall knowledge of barrier-free design. The 200-page three ring binder includes illustrations of products, prices and ordering information. The book is $50 and may be ordered from: Julee Quarve Peterson, Inc., P.O. Box 28093, Crystal, MN 55428.

"Take Care!" is a 30-page booklet outlining a self care program for caregivers. It features strategies, exercises, ideas and helpful techniques for coping with the pressure and stress that are naturally a part of caregiving. Topics include managing stress, nurturing self esteem, identifying and coping with difficult feelings identifying and using community resources, reducing negative thinking, maintaining a positive outlook asking for support and setting realistic expectation. The cost is $2.50 and it is available from: Amherst H. Wilder Foundation, Take Care!, 919 Lafond Av., St. Paul, MN 55104.

EMPLOYMENT OPPORTUNITIES

Director, Community Outreach Programs

A psychologist is needed to provide clinical direct-service consultation and supervision of personnel providing multidisciplinary direct services to people with developmental disabilities and severe behavior problems at the University of Minnesota. Person applying for the position should have a minimum of three years post-doctorate experience and be licensable as a Licensed Clinical Psychologist in the state of Minnesota within 12 months of employment. Opportunity to practice clinical/behavioral psychology within an academic environment and actively participate in research opportunities pertaining to treatment for people with developmental disabilities and severe behavior problems. Salary range $30-40,000. For additional information, please contact Dr. Travis Thompson, Director, Institute for Disabilities Studies. Send letter of application and vitae to: Dr. Travis Thompson, Institute for Disabilities Studies, University of Minnesota, 2221 University Av. SE., Suite 145, Minneapolis, MN 55414. (612) 627-4500. Deadline for application is January 31, 1990.

CALL FOR HELP

Janice Meuwissen, a mother of an 18-month old girl with a diagnosis of microcephaly, is interested in networking with other parents who have children with the same diagnosis. She is interested in hearing about success stories, new ideas, new programs or new therapy techniques. She will share the information with others and hopes to begin a newsletter. If you have information to share with her, send it to Janice Meuwissin, 4521 Chatham Rd., Columbia Heights, MN 55421 or call (612) 573-1641.

RECREATION

The Vinland National Center in Loretto is sponsoring a "Fun and Fitness Days" event for adults with physical disabilities on November 24-26 and December 18-20. Activities will include stress management, weight room, relaxation techniques, snowshoeing, nutrition awareness, ropes course, general fitness and much more. Vinland serves people with disabilities in Hennepin county at no cost to the participant. The event includes food, lodging, equipment and instruction. Register by November 10. Call Marie at (612) 479-3555. For further information, contact: Vinland National Center, Lake Independence, P.O. Box 308, Loretto, MN 55357.

WORKSHOPS

November 17

"A Positive Approach to Educating People with Developmental Disabilities on AIDS and Sexuality" is a workshop sponsored by United Cerebral Palsy of Minnesota. It will be held at the Radisson Hotel University, 615 Washington Av. SE., Minneapolis from 8 a.m. to 4 p.m. The workshop is intended for professionals, family members, advocates and people with developmental disabilities. Geoffrey B. Garwick and Claudia Swanson, both of Ramsey County Human Services, are the presenters. Their approach is to teach positive skills to cope with the negativity surrounding AIDS and H.I.V. It stresses learning which is positively applied in a variety of practical circumstances to build on a person's strengths and interests. The registration fee is $6 for people with developmental disabilities, $12 for family members and $30 for professionals, The fee includes lunch and breaks, and scholarships are available. Register by November 14 and send to: UCP of MN, Inc., Suite S-233, 1821 University Av., St. Paul, MN 55104. For further information call 646-7588 or 1-800-328-4827, ext. 1437.

November 18

"Worth the Effort: Advocating for your Child Who is Hearing Impaired" is a workshop sponsored by the Minnesota Foundation for Better Hearing and Speech's Parent Network. It will be held from 9 a.m. to 3:30 p.m. at the University Building, 1200 S. Broadway, Room 120, Rochester, MN. Topics to be covered include federal and state laws, laws on early intervention (ages 0-7), techniques for parents, parent viewpoints and communication skills building. There is no fee for the workshop. Register by November 10 with Carolyn Anderson, Parent Network Specialist at (612) 223-5130.

December 12-13

"Non Aversive Behavior Modification" is a workshop for professionals charged with the design and implementation of behavioral programs. The workshop will cover a rationale for nonaversive behavior modification, the context of positive programming, behavioral assessment, alternatives to punishment and case studies. Presenters will be Gary W. LaVigna, Ph.D. and Thomas J. Willis, Ph.D. both of the Institute for Applied Behavior Analysis. The workshop is $85. It will take place at the New Ramada Inn-Bloomington, 4460 W. 78th St. Circle, Bloomington from 9 to 4:30 both days. Send registration by November 15 to: Institute for Applied Behavior Analysis, 6169 St. Andrews Rd., Ste. 123, Columbia, SC 29212.

December 14

"Maximizing Staff Consistency in Program Implementation" is a workshop on increasing program effectiveness for individuals with special needs. The workshop focus is on learning to use the Program Status Report (a staff evaluation and feedback system proven to maximize staff consistency in program implementation) and the Procedural Reliability system (a system of checks to ensure accurate program implementation). The fee is $75. Registration deadline is November 15. The speakers and registration address are given in the Dec. 12-13 announcement above.

EDUCATOR SUPPORT GROUPS

Minnesota educators committed to building integrated school communities have the opportunity to share support, experiences and ideas with other like-minded professionals during monthly "Educators for Integration Support Group" meetings held throughout the state. The groups, sponsored by the Minnesota Integrated Education Technical Assistance project, are open to educators and other school personnel seeking to better serve students with severe disabilities in regular classes and other typical school and community environments. Beginning in September, monthly meetings will be held in three locations around the state throughout 1989-90. Information on each support group follows. To be on the mailing list for the support group in your area, call the contact person and provide your name and address.

- **Metro Area.** Meets second Monday of each month, 7-9 p.m., AccessAbility, Inc., 360 Hoover St. NE, Minneapolis. Contact Terri Vandercook, (612) 624-4848.
- **Duluth Area.** Meets second Thursday of each month, 7-9 p.m., Central Administration Bldg., Lake Av. and 2nd St., Duluth. Contact Eve Davis, (218) 722-6809 or Carolyn MacArthur, (218) 879-8955.
- **St. Cloud Area.** Meets second Monday of each month, 7-9 p.m., Westwood Elementary School, 5800 Ridgewood Rd., St. Cloud. Contact Ron Watkins, (612) 253-5857.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
November 1989

Developmental Disabilities Program
300 Centennial Office Bldg.
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
(612) 296-4018

MINNESOTA RECEIVES FEDERAL GRANT TO ACCESS TECHNOLOGICAL ADVANCES FOR PERSONS WITH DISABILITIES

Governor Rudy Perpich announced on October 12, 1989, that Minnesota will be the recipient of a $500,000 grant from the National Institute on Disability Research and Rehabilitation, U.S. Department of Education. Federal officials have also recommended that Minnesota be awarded an additional $1 million grant over the next three years. This grant originates from legislation passed by the U.S. Congress-- Technology Related Assistance for Individuals with Disabilities Act (Public Law 100-407).

Minnesota is one of the first nine states awarded grants for the development of a comprehensive, consumer-responsive, statewide system of technology devices and services for people with disabilities. Forty-seven states competed for this grant.

Governor Perpich has had a strong interest in applying new technological advances to meet the needs of persons with disabilities so that they can live as independently as possible. In 1986, Governor Perpich initiated an Advisory Council on Technology for People with Disabilities. Many features of the federal legislation was modeled after Minnesota's successful example. The Governor's Advisory Council is a public-private entity which helps to develop public policy on the use of technology by people with disabilities. Goals of the Council include: (a) to improve information collection and dissemination,
(b) to increase awareness, and (c) to encourage funding, research, and development.

One special feature of the Minnesota grant is to increase the awareness and availability of technology for people with disabilities. Activities of the grant will include: information and referral service; consumer task force on insurance; mobile van service to provide on-site modification of technology; and a grant program to community-based organizations to develop local technology.

For more information, contact: Rachel Wobschall; Governor's Advisory Council on Technology for People with Disabilities; 208 Metro Square Building, St. Paul, MN 55101. Tel. (612) 297-1554.

'IT'S ABOUT RELATIONSHIPS' EXCERPTS FROM AN ESSAY BY MARSHA FOREST

The following passages are from a chapter that will appear in *Critical Issues in the Lives of People with Severe Disabilities*, by L. Meyer, C. Peck, and L. Brown (Eds.), which is in press at the Paul H. Brookes Publishing Company. This essay may also be purchased in its entirety in booklet form from The Frontier College Press, 35 Jackes Avenue, Toronto, Ontario M4T 1E2.

Marsha Forest is the Director for Education and the Director of the Centre for Integrated Education at Frontier College in Toronto. Excerpts from her essay, "It's About Relationships," read:

Introduction: "The message in Alice Walker's beautiful children's book, *To Hell with Dying*, speaks volumes to me personally: 'To the old ones of my childhood who taught me the most important lesson of all: That I did not need to be perfect to be loved. That no one does.'" All I really ever wanted in my own life was a group of people around me and especially one central person in my life who would just love me totally as I am."

". . . I (have) met two people who changed my life both personally and professionally--Jack Pearpoint and Judith Snow. They are both entwined with me on this journey to create a world where people are loved for whom they are and cherished for the gifts they have to offer."

"I am not at all interested in disability, mental retardation, or special education. I am, however, passionately interested in being part of building a just and humane society where each human being can live in dignity and have his/her needs met--whatever that may involve."

"I strongly believe we have the money and resources to do the above."

Force One: "In 1981, U.S. President Ronald Reagan announced a force of 100 B-1B Bombers. . . to enter service in 1988 at a cost of $28 billion. This, to me is obscene and not rational. The cost is beyond my wildest notions of money. I know Judith Snow needs $60,000 to run a decent attendant care system. I know that $5,000 would go a long way to help the Frank family. Let's be honest . . . money in the trillions is there for weapons that kill, maim and destroy the human race. Can you imagine if we used that money to help people?"

"To talk about integration without looking at the wider social issues of war, poverty, illiteracy, etc., is foolish. . . . (T)he movement to bring children back into real classes where they belong is simply one part of a wider social movement to create a just society which is fit for human existence."

"Is this possible? YES! Will it happen tomorrow or without an enormous amount of hard work? NO!"

The Challenge: "Bringing people who have been excluded on the basis of race, class, sex, or handicapping condition back into the mainstream is an exciting, controversial, and dynamic process for it challenges the basic assumptions of each of us and at the same time introduces us to new ways of thinking and seeing."

"I was not born thinking like I do today. I accepted the notion that people with disabilities needed institutions, special care, special education, special housing.. . . As I got to know my friend Judith Snow and as I became involved in her struggle to get out of a chronic care nursing home, I learned about the reality of life for most people with disabilities. I was angry and disgusted at the injustice of it all."

"Judith was my friend. . . .She had two choices--live or die. I learned that when you love people as they are, you stand with them and fight with them and laugh and cry with them. You don't try to change, adjust, or cure them. . . . You won't take the 'least restrictive environment'--you want the BEST, the MOST. You never want the least for those you love."

"The attitudes of wanting perfection start at birth. . . Just this week a friend of ours gave birth one month prematurely to a three pound baby who is said to be 'profoundly' brain damaged. The advice given by the physicians is 'don't bond with the baby--she will probably die, or at best be a burden to you for the rest of your lives.'"

"What kind of world is this where we tell parents not to love a child? No one has any idea what this baby will become. . . . No one can predict. The message NOT TO LOVE is mean, cruel, horrible. Love the baby if it's perfect. Hate the baby if it's imperfect in any way. Love me if I live the life you want. Hate me if I am not perfect in your eyes. Throw me away if I am different. Get rid of me if I am unique."

"It starts in the hospital--it too often ends in a nursing home."

The Karate Class: "Why can't the school system act more like my Karate Class? Patty (my tutor who has a black belt--the top) gently guided me through the exercises (on my first day) helping place my feet in the right position and always making me feel I was doing okay. I went home elated. I had lived through a Karate class at the age of 46. I was sore in body but elated in spirit! . . . The moral of the story is that I experienced integration/inclusion first hand and I loved it. I was welcomed and included from the first moment I walked into the studio. I know schools can do this too. . . it is a matter of will, choice, and values. It is our future."

The Emperor is Naked--The Myth of Special Education: "I think we've lost our hearts to a myth of special education. . . . (As a trained special education teacher,) I realized that the power of the segregated environment was teaching negative messages daily. The environment said, 'You are not good enough to be part of the real school--we don't want you with us.' I couldn't give my students what they need most--real experiences and real relationships in a real school/a real classroom. I saw that the Emperor (special education) was naked (not working)."

"Let's look at some of the ridiculous things we do:

- If a child needs more relationships--we give him less; we will meaningfully assign an educational assistant and build one-to-one dependency.
- If a child needs more time--we give her less hours at school and more hours riding around town to 'segregation land' in a 'special bus.'
- If a child needs normal behavior models--we give him six other kids, who scream, as his 'pals' and then we wonder why he doesn't improve."
- If a child needs more communication--we put her in a room with ten other kids who don't communicate well and again we wonder why she won't learn."

"'But, tell me how to do it,' teachers in frustration ask me. Bringing back children who have been historically left out brings back our humanity. You can't teach the value of love or diversity or tolerance by preaching or lecturing AT people--we all have to live these values and have real situations to test our morality and humanity. . . . What to do comes out of a team problem-solving process of adults and children who together come up with creative solutions to unique challenges."

Microwave Thinking and Feeling: "Society today wants the quick fix, the quick high. Teachers seek out the 'answer.' Well, we mustn't give in. Good teachers know that real learning takes time and that education is a journey and a process. Inclusion won't cook fast in the microwave."

Conclusion: "The greatest diseases in North America today are loneliness and meaninglessness. Bringing back the least powerful into our schools is an incredible antidote to the consequence of these diseases--suicide, alcoholism, and drugs. Helping one another is a beautiful thing, but it's not something you simply talk about--it is something you do."

"Special Education is an idea whose time is up. It is now time to build inclusive communities where together we can teach our nation to love as well as to read and write. We need most of all to believe fully and finally that ALL truly means ALL. . . . We need to do it right now so we won't have to publish papers like this in 20 years!"

APPLICANTS SOUGHT BY PARENT CASE MANAGER PROJECT

The Institute on Community Integration at the University of Minnesota, under a grant from the Governor's Planning Council on Developmental Disabilities, will be replicating the Parent Case Manager Project (piloted in Dakota County), and will be expanding the project beyond the metropolitan area. The new title of this project is "Self-Determination and Empowerment for Persons with Developmental Disabilities."

Through training and support, the intent of the project is to empower individuals so that they can participate more fully in the case management of services being delivered to themselves or their sons and daughters. Applicants should live in the Northwest, Northeast, and Southwest/West Central regions of Minnesota.

Applications are due by December 1, 1989. Selections will be confirmed in January 1990. The first training sessions will be held in February 1990 at the Bemidji, Hibbing, and Southwestern Technical Colleges.

For an application form and for more information, contact: Marijo McBride; Institute on Community Integration; University of Minnesota; 6 Pattee Hall; 150 Pillsbury Drive, Southeast; Minneapolis, MN 55455. Tel. (612) 624-4848 or 627-4624.

PUBLICATIONS/RESOURCES

ADDVANTAGE is a quarterly newsletter relating to aging and developmental disabilities. It is published by the Rehabilitation Research & Training Center Consortium on Aging and Developmental Disabilities. The Center Consortium is comprised of seven universities in six states, including the University of Minnesota. The mission of the Center is to develop and implement a program of research and training directed at improving community integration of older persons with developmental disabilities. The newsletter includes federal and state policy initiatives, research implications, exemplary practices, and more. For a free subscription, please contact: Evelyn Sutton, Rehabilitation Research and Training Center; Consortium on Aging and Developmental Disabilities; University of Akron; 159 Carroll Hall; Akron, Ohio 44325-5007. Tel. (216) 375-7956, or (216) 375-7243.

Preventing Dental Diseases in Children with Disabilities, Johnson & Johnson Dental Care Company, Academy of Dentistry for the Handicapped, American Dental Hygienists' Association and Association for Retarded Citizens-US, 1989. For a number of reasons, children with disabilities are more prone to dental disease due to oral conditions, physical limitations, special diets, and medications. This helpful packet of information sheets covers: at-home oral care; positions for cleaning teeth; brushing, flossing and rinsing; professional dental care; common dental problems; growth and development; checklist for selecting a dental office; and tips for planning successful dental visits. For a free copy of this kit, please contact: Ann Balson; ARC-US; 2501 Avenue J; Arlington, TX 76006. Tel. (817) 640-0204.

The G. Allan Roeher Institute Catalog 1988-1989: Films, Videos, Publications. The G. Allan Roeher Institute in Canada provides current information to the public, professionals, and community groups. One of the Institute's goals is to identify and anticipate future trends that will support the presence, participation, self-determination, and contribution of persons with an intellectual impairment in their communities. Another goal is to foster the exchange of ideas leading to new ways of thinking about persons with an intellectual impairment. This catalog offers a wealth of resources for parents, professionals, and persons with disabilities. Contact: The G. Allan Roeher Institute; Kinsmen Building, York University, 4700 Keele Street, Downsview, Ontario, Canada M3J 1P3. Tel. (416) 661-9611.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

LENDING LIBRARY SELECTIONS

Equality in Education, Section 504, produced by the Office of the Assistant Secretary for Civil Rights, United States Department of Education (Videotapes, 1/2 inch VCR). Three videocassettes focus on the rights of students with disabilities under Section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination on the basis of physical or mental disabilities in programs and activities that receive federal financial assistance. The tapes are entitled:

Equality in Education, Section 504, in Elementary and Secondary Programs (36 minutes);

Equality in Education, Section 504, in Education and Employment (25 minutes);

Equality in Education, Section 504, in Postsecondary Programs.

A brochure accompanies the tapes: ***The Rights of Individuals with Handicaps Under Federal Law*** (1988).

A Normal Life (20 minutes), produced by the Minnesota Department of Human Services, 1989. This production chronicles the progress of group homes operated by Minnesota regional treatment centers. It includes interviews with employees, residents, parents, and an employee of one of the residences.

In the Sunshine (14 minutes), produced by the Association for Retarded Citizens of Minnesota, 1989. Filmed in various locations in Minnesota, this production depicts the quality of life for individuals with multiple disabilities who have moved from state operated regional treatment centers to homes in community settings. Parents testify that their sons and daughters are "better off," get closer supervision, have more opportunities to make choices and do things for themselves.

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D D INFORMATION EXCHANGE

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REALIZING THE VISION ACCOMPLISHMENT

Problems in Paradise

A Guest Column
by Thomas J. Zirpoli, Ph.D.

David is a young adult who lives in a downtown apartment in a midsize city. David is mentally disabled. His background is a common story. Early in life he was institutionalized because the professionals said it was the best thing for everyone involved. At about 14 years of age he was placed in a smaller residential facility closer to home as part of a new community placement movement. Three years later it was decided that David was ready to go home. After a few years of living with his parents, David moved into a group home, and three years after that he was placed in his current "independent" apartment. David lives there, independently, with a little support.

Imagine, many say, here is this young man, previously destined to spend his life in an institution, now living in the community. We saved David and many others like him from the ravages of purgatory. We are setting the captives free. How wonderful the progress we have made.

But, there are problems in paradise. David, although not physically disabled, doesn't yet have all the skills necessary to live independently without significant support. Without this support, David may not bathe, shave, or care for any other basic, personal hygiene needs. He may not wash his clothes or clean his apartment. He may forever sleep on the same sheets, the same pillow case. His clothing may be inappropriate for the weather. He may live on Coke drinks and never have a balanced meal.

David has the ability to learn all of the above skills. For whatever reason, however, David does not, without significant support, bathe, shave, wash his clothes, clean his apartment, change his sheets, dress appropriately, and eat nutritious meals.

We are proud of David's community placement. We are proud of all the people who have been deinstitutionalized and saved from "living" their lives isolated from the real world, with no other human contact but others with disabilities and paid caregivers. We should be proud. The past and ongoing progress to provide persons with disabilities a place among the living to live in an integrated, real world has been, and continues to be, an honorable, morally right, and mighty battle.

But, there are problems in paradise. David, and thousands of others like him, are in trouble. They are in trouble because not all persons involved in the community placement battle are honorable. Some have different motives for their participation in this mighty battle. Honorable motives for community placement and independent living are based upon human rights and the dignity of a quality life for all. The motives of many, however, are based upon the lack of resources; issues of funding are at the heart of these actions.

Appropriate community support for persons with disabilities requires that caring and skilled people be available to provide whatever levels of support are necessary. It requires that honorable governments and private business recognize these needs and put forth the necessary resources for these needs.

There are problems in paradise. The goal of "independent living" is being used as a smoke screen for insensitive enterprises, public and private, that fail to provide appropriate community support for persons with disabilities. The right of "free choice" is the response to parents who ask why their son has not been encouraged to take a bath or cook a meal. The honorable goals and rights for persons with disabilities are now frequently used as smoke screens to cover up a new purgatory.

Failure to take action on these problems presents another, more serious, problem for the future of persons with disabilities and the right to live full, integrated lives. There are many people who will use these new purgatories as examples of how deinstitutionalization has failed. They will use these examples just as we, years ago, used the institutional examples of purgatory as evidence of a failed system needing serious attention. Many people who are still fighting the deinstitutionalization movement-and there are many-are waiting with an "I told you so." "We warned you," they will say, "about the lack of appropriate supervision and care provided in community placements." "At least in the institution," they will say, "I knew my son/daughter was safe.

The cries of "foul" are being voiced by many parents and some professionals. Like the professionals, David's parents are also proud of the progress he has made moving from an institution to his current community placement. They don't want David to return to a more restrictive environment. But they recognize that David is not safe where he is unless appropriate support is provided. Right now, because no one else is providing the appropriate level of support that David needs (in the name of "independence" and "free choice"), David's parents are his significant support system. They wonder, however, who will be there for David when they are no longer able to provide the support he needs.

Must conditions in some community settings fall to the same state of affairs as the old institutions did before we act? And what actions are appropriate? Clearly, we need some monitoring of public and private community placements. Clearly, some basic standards of support are appropriate for these community programs. We must not wait for conditions to reach crisis proportions. We must not wait, as we seem to always do, for parents to go to court in order to get our attention. We must not wait for this issue to become a political one--a battle we will surely lose given the current conservative political climate.

We must continue to push for greater integration and more community placements. However, I fear that some have failed to recognize this as only a first step. As professionals and as concerned family members, we must ensure that these community placements are safe and that appropriate support systems are in place. I, for one, would like to see a greater amount of attention focused on this critical issue and I welcome your comments.

Our guest columnist, Dr. Zirpoli, is chairperson of the Critical issues Committee for The Association for Persons with Severe Handicaps (TASH). You may send your comments to Tom Zirpoli, Box 5017, College of St. Thomas, St. Paul, MN 55105.

FOR YOUR INFORMATION

Communication Assist For Sale

A slightly used Special Friend Speech Prosthesis (scanning unit, pre-programmed and programmable) is for sale. The prosthesis is a lightweight portable speaking device for use by non-vocal people and professionals who work with non-vocal people. The price is $2,500. For more information, contact John Krumm at the Robbinsdale Area Schools, Special Education Department, 4148 Winnetka Av. N., New Hope, MN 55427; (612) 533-2781, ext. 296.

Human Services Referral and Placement Service Available

The Social Service Network is a personnel consulting firm that provides temporary social service staff in human service programs such as group homes, DACs and supported employment programs. Staff are screened to meet the qualifications, standards and requirements of the requesting agency. Staff positions available include job coach, residential assistant, therapist, community trainer, Rule 186-funded positions, and more. This service can assist agencies experiencing difficulty filling positions or during periods of turnover. For further information, contact Sue Santa, Social Service Network, 2402 University Av. W., Suite 204, St. Paul, MN 55114; (612) 645-8610.

Parent Support Group

The Minnesota Association for Persons with Severe Handicaps and the ARC Minnesota are sponsoring monthly support groups for parents of children with moderate to severe disabilities. The meetings are facilitated by various advocacy organizations. Created for parents interested in having their children included in regular classes and other aspects of school life, the groups provide a forum for sharing strategies, successes, challenges and support. The meetings are being held the third Saturday of each month from 10 a.m. to noon at ARC Minnesota, 3225 Lyndale Av. S., Minneapolis. For further information, contact Jennifer York at (612) 624-4848.

RECREATION

The Division of Recreation, Park and Leisure Studies at the University of Minnesota has received a three-year grant from the U.S. Department of Education. This project will train therapeutic recreation students in the "best professional practices" to assist children with severe developmental disabilities to successfully participate with their nonhandicapped peers in existing community recreation experiences. The co-directors of the project, Dr. Stuart J. Schleien and Dr. Leo H. McAvoy, will be working with students, community leisure service agencies, children with and without severe developmental disabilities, parents and other community agencies to develop and evaluate integration strategies. A number of community recreation and school sites in the Minneapolis/St. Paul area will be involved as project model program sites. The project will support five graduate student assistants while they complete coursework, practicum experiences, and research projects on community recreation integration and persons with severe developmental disabilities. Anyone interested in applying for these graduate assistant positions over the next three years can contact Dr. Schleien or Dr. McAvoy at 203 Cooke Hall, 1900 University Av. S.E., University of Minnesota, Minneapolis, MN 55455; (612) 625-5300.

EDUCATIONAL OPPORTUNITIES

The Institute on Community Integration is offering two classes at the Minneapolis campus of the University of Minnesota. The classes are open to extension students through special registration.

"Family-Professional Planning for Persons with Severe Handicaps" (EPsy 5609), offered winter 1990, will have Terri Vandercook as instructor. This interdisciplinary course examines the needs of families including children with severe developmental disabilities with emphasis on life cycle needs, service issues and programs of support from infancy through adult years, services from different agencies and disciplines, and professional requirements and responsibilities in serving families.

"Case Management: Trends and Practices in Serving Persons with Developmental Disabilities" (SW 5010), offered spring 1990, will have Edward Skarnulis as instructor. This course provides a foundation in case management (service coordination) for persons with developmental disabilities. Included in the discussions are historical perspectives, state regulations, development of individualized plans, values, current best practices, transitions issues, and quality assurance.

For further information on registration for these classes, contact the extension office at the University of Minnesota at (612) 625-3333 or the Institute on Community Integration at(612) 624-4848.

FUTURE CONFERENCES

May 27-31, 1990

The American Association on Mental Retardation has announced its 114th annual convention at the Atlanta Hilton. The theme will be "A Better Way of Life: Policy Research and Practice." Robert Bruininks, director of the Minnesota Institute on Community Integrations and AAMR president-elect, has announced the following sub-themes:

- Health and Social Issues in Preventing Mental Retardation;
- Full Integration Through Community Living;
- Integrated Education and Effective Schools;
- Increasing Independence Through Technology, Learning and Training; and
- Empowering Families and Consumers.

For more information, contact AAMR at (800) 424-3688.

PUBLICATIONS

1989 KidsGuide

This publication by editor/publisher Dennis Schapiro is a resource guide for parents, teachers and human service professionals. It is an "inventory of tools available for doing the work and finding the joys of parenting. It is also, in part, a commentary on the issues facing children and our future." Topics covered include free things, adoption and foster care, child care, child protection, physical and developmental disabilities, health care, intercultural opportunities, learning outside school, libraries, mental health, nutrition, old and young, parenting, parties, pets, retail, schools, sports and fitness, summer camps, volunteering, and youth programs. The publication is available at a discounted price of $4.95 from United Cerebral Palsy of Minnesota, 1821 University Av., Ste. 233-South, St. Paul, MN 55104.

Integration Poster

"Learning Together...Integrated Schools Today...Inclusive Communities Tomorrow" is the message on a new poster which depicts children from around Minnesota learning together. The poster was jointly sponsored by the Minnesota Association for Persons with Severe Handicaps (MNASH), the Institute on Community Integration and the State Department of Education. The 17 x 22 inch color poster is being sold for $5 each or five for $20. For mail orders send a check payable to the University of Minnesota to: Learning Together Poster, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive S.E., Minneapolis, MN 55455. All proceeds from the poster will be used to support the attendance of educators, parents and consumers at conferences and workshops on the topic of quality integrated education. Individuals wishing to apply for financial assistance to attend a training opportunity on integrated education may send their request to: MNASH Integration Team, 1218 No. Victoria, St. Paul, MN 55117.

Leisure Publications

Swimming: An Introduction to Swimming, Diving, and SCUBA Diving for Blind and Physically Handicapped Individuals is the third and newest in a series of leisure-pursuit booklets to be published by the National Library Service for the Blind and Physically Handicapped (NLS). The booklet features articles on Trischa Leanna Zorn, a legally blind swimmer, who has won 70 gold medals in national swimming competitions and 30 four medals internationally. The booklet also cites other printed materials available on swimming and lists activities and organizations, including classes, programs and associations. The other two booklets are *Birding: An Introduction to Ornithological Delights for Blind and Physically Handicapped Individuals* and *Fishing: An Introduction to Fishing for Fun and Food for Blind and Physically Handicapped Individuals.* The NLS plans to publish one new leisure-pursuit booklet in the series each year. The booklets are available upon request from the Reference Section, National Library Service for the Blind and Physically Handicapped, Washington, DC 20542. The publications are available in large print, on disc and in braille.

Education Information

The ARC Ohio has produced a publication to assist parents in the job of ensuring the best possible education for their children with disabilities. *"Monitoring Educational Programs: A Guide for Parents"* is designed to help parents give teachers and administrators constructive input regarding the educational experience of their child. It has been developed upon the philosophical principles of integration and least restrictive environment. To obtain a copy of the guide, sent $1 to ARC Ohio, 360 S. Third St., Suite 101, Columbus, OH 43215.

Newsletters

The Institute on Community Integration offers three newsletters to interested persons. *"What's Happening"* is written for young adults to enable them to become more socially active through participation in the activities profiled in each issue. *"What's Working in Integrated Education?"* is an annual publication which provides updates on integrated education practices and progress in Minnesota. The third--*"What's Working in Supported Employment?"*--is of interest to people concerned with the latest practices and publications in the area of transition and supported employment. To be added to the mailing list for any or all three newsletters, contact Vicki Gaylord, Publications Coordinator, Institute on Community Integration, University of Minnesota, 13 Pattee Hall, 150 Pillsbury Dr. S.E., Minneapolis, MN 55455.

TRAINING OPPORTUNITY

The Epilepsy Education program at the University of Minnesota has recently completed a training package about epilepsy. The package, entitled "Epilepsy: A Positive I.D.," is designed to help health educators, epilepsy educators and health professionals recognize the most common epileptic seizures, administer first aid and recognize epilepsy medication. A 22-minute videotape demonstrates the two types of seizures most frequently encountered, generalized tonic-clonic (grand mal) and complex partial. It emphasizes that complex partial seizures can easily be mistaken for drunkenness or drug abuse. The videotape is a blue-ribbon winner in the 1988 American Film Festival and won the Gold Award at the 1989 International Epilepsy Audiovisual Festival. An instructor's manual with a complete lesson plan, pre- and post-test, first-aid tips and reference material is also provided for trainers using the video. The complete package costs $100. It can be rented for $25. For more information, please call (612) 331-4477, or write to Epilepsy Education, University of Minnesota 2701 University Av. S.E., Minneapolis, MN 55414.

INFORMATION EXCHANGE

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December 1989

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Minnesota State Planning Agency
Roger Strand, *Editor*
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BETTY HUBBARD'S DEATH LEAVES LEGACY OF CHALLENGES

On October 13, 1989, Betty Hubbard died. As a leader in the field of developmental disabilities in Minnesota, as a former member of the Governor's Planning Council on Developmental Disabilities, as an involved citizen, and as a friend to many, she will be deeply missed. Last April 1989, Toni Lippert presented Betty with an award initiated in her name on behalf of the Minnesota Association for Persons with Severe Handicaps. Toni's words, at that time, expresses our thoughts the best:

"Her style is deceptively simple, but difficult for most of us to emulate. Her vision is only what should be. She leads us to judge what is needed to achieve the vision-- totally, totally unfettered by what is presently available or permitted. She teaches us how to negotiate around preconceived policies and set funding paths. She has the capacity to make those participating, cooperative and sharing of "what should be." Parties to such negotiations realize success and satisfaction, not only for the person with a disability, but for themselves. She has taught us the value of partnerships, of team effort."

"Betty, your legacy to people with disabilities is that, for everyone of them and those to come, a life of dignity, support, and community is truly possible. Your legacy to parents, advocates, and providers of service is that you have shown us the way to make this possible."

STATUS REPORT ON EDUCATION SUBMITTED TO THE PRESIDENT AND CONGRESS

The National Council on Disability recently released *The Education of Students with Disabilities: Where Do We Stand?: A Report to the President and the Congress of the United States* (September 1989). The following information comprises only selected excerpts from the report:

"Today, the education of students with disabilities is at a crossroads. The focus over the past 14 years . . . has been on processes and procedures related to special education with access to a public education as the goal. The time has come to shift the focus to quality and student outcomes. Simply assuring that services are present or placing students with disabilities into general classrooms is no longer good enough."

"The time has come to ask the same questions for students with disabilities that we have been asking about students without disabilities: Are they achieving? Are they staying in school? Are they prepared to enter the work force when they finish school? Are they going on to participate in postsecondary education and training? Are they prepared for adult life?"

"For the most part school reform efforts have not been directed toward addressing the special challenges that students with disabilities face. There is a perception that students with disabilities have a separate system, called special education, that will address all their needs. There is a separate funding stream, separate classes, separate teachers, special rights, etc. Many believe that they are well provided for in their separate system, and in fact better provided for than many other groups of students."

"But, when we pause and compare the outcome indicators for students with disabilities and indicators for students without disabilities, a different picture emerges.. . . It appears that students with disabilities are significantly lagging behind."

"Where only 15 percent of all adults aged 18 and over have less than a high school education, 40 percent of all persons with disabilities aged 16 and over did not finish high school (Harris and Associates, 1986)."

"Where the dropout rate is 25 percent for all students, it is 36 percent for students with disabilities (Wagner, 1989)."

"Where 56 percent of all students participate in postsecondary education programs, only 15 percent of students with disabilities do (Wagner, 1989)."

"While the unemployment rate is about 5 percent nationally, a full 66 percent of all 'Americans with disabilities between the age of 16 and 64 are not working' (Harris and Associates, 1986)."

"By any standards, these statistics are not acceptable. They indicate that access to education is simply not enough and that we have a lot of work to do."

Study and Findings

Some of the findings resulting from a one-year study by the National Council on Disability were:

- Parent-professional relationships too often are strained and difficult, and parents and professionals frequently view one another as adversaries rather than as partners.
- Some parents have difficulty finding appropriate services for their children.
- Parents and students report that some schools have low expectations for students with disabilities and establish inappropriate learning objectives and goals.
- Services often are not available to meet the needs of disadvantaged, minority, and rural families who have children with disabilities.
- There is a perception that the outcomes of due process hearings are biased in favor of the schools.
- Many parents are uninformed about their rights under the law.
- Most school reform initiatives appear to be a response to declining academic achievement rather than efforts to find ways for schools to meet the diverse needs of all students.
- An essential aspect of school reform is the professionalization of teaching.
- School reform efforts have not specifically addressed the diverse needs of students with disabilities.
- Current pedagogy regarding effective schools and teaching practices can facilitate the integration of special needs students into general classrooms.
- The federal government has not fulfilled its promise of 40 percent funding for the cost of providing education to students with disabilitiess.

Recommendation

The National Council on Disability recommended that a two-year National Commission on Excellence in the Education of Students with Disabilities be funded by the U. S. Congress. The Commission would continue an assessment of the status of the education of students with disabilities and make recommendations regarding how the quality of education for students with disabilities could be enhanced and how improved student outcomes could be realized.

The twenty questions to be addressed by the Commission are as follows:

"How can the special education community join the general education community in a partnership to assure that the goals of equity and excellence are pursued simultaneously in national school reform efforts?"

"How can the special education community and the general education community collaborate to further consolidate the special education and general education systems for the benefit of all students?"

"What steps can be taken to assure that the movement toward providing services for students with disabilities in their neighborhood schools continues and that the services are appropriate?"

"How can the pedagogy associated with special education be brought to bear in general education classrooms?"

"What is the relationship between the educational setting and student outcomes?" Commentary: "What is needed for the 1990s and beyond are newly conceptualized models of service delivery which will result in integration with adequate services."

"In the 1990s what is the appropriate federal role in the education of students with disabilities as we continue to focus on developing excellence in educational services for students with disabilities?"

"What can be done to further enhance the Federal-State partnership that is so critical to the effective implementation of P.L. 94-142?"

"How can federal compliance monitoring for P.L. 94-142 be improved to (1) more meaningfully involve parents, (2) be more timely, and (3) ensure full compliance with the law?"

"How can effective parent-professional relationships be established and maintained as a component of an appropriate education program for students with disabilities?"

"What steps can be taken to assure that students with disabilities in minority, rural, and disadvantaged communities have full access to appropriate educational services?

"How can students with disabilities whose parents serve in the military be afforded the same equal educational opportunity as all other eligible students?"

"What steps can be taken to assure that all parents of students with disabilities are fully informed of, and understand their rights under P.L. 94-142?"

"What are the minimum competencies and training requirements for due process hearing officers?"

"How can information about the due process system, including outcomes of due process hearings and relevant court decisions, be disseminated nationally to parent organizations, state and local policymakers, and other entities concerned with the education of students with disabilities?"

"Is there an expanded role for institutions of higher education in the development of innovative personnel preparation programs that prepare educators to work with students who have a range of diverse needs?"

"How can schools provide an individualized transition plan for every high school student with a disability and ensure coordination between the school and adult service agencies or postsecondary education and training programs?"

"What steps are necessary for schools to provide:
(1) a comprehensive curricula that includes extensive community-based vocational experiences as a primary component of each high school student's individualized educational program and (2) job placement at the time of graduation for all students who want to work?"

"How can school and businesses effectively form partnerships, particularly at the local level, to collaborate on employment-related curriculum and training programs for students with disabilities?"

"How can the special education community take the lead in educating the business community about the abilities and talents of students with disabilities and the contributions they do and can make in the workplace?"

"How can the United States best coordinate with other countries in sharing information and resources regarding effective educational practices for students with disabilities?"

Copies of the entire report may be requested from: National Council on Disability; 800 Independence Avenue, Southwest, Suite 814; Washington, DC 20591.

References:

Harris, L., & Associates. (1986) *International Center for the Disabled Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream.* New York: Author.

Harris, L., & Associates (1989). *International Center for the Disabled Survey III: A Report Card on Special Education.* New York: Author.

Wagner, M. (1989). *The transition experience of youths with disabilities; A report from the national longitudinal transition study.* Menlo Park, CA: SRI International.

TRAINING IN PERSONAL FUTURES PLANNING SCHEDULED IN JANUARY

Introductory training in Personal Futures Planning will be available in Greater Minnesota during the month of January 1990. Personal Futures Planning is an interactive, individualized planning process designed to focus on what is possible for people; on what preferences, strengths, and desires people have; and on what ways they can contribute these qualities to their communities. Workshop participants must clarify and reconcile their own values and personal theories about "quality of life" as they support the future of another person.

These workshops are sponsored by the Human Services Research and Development Center in St. Paul, and are funded by a grant from the Governor's Planning Council on Developmental Disabilities.

One-day workshops will be conducted by Jane Wells. Each workshop is scheduled from 9:00 a.m. to 4:30 p.m. on Thursdays at the following locations:

January 11--Best Western, Thief River Falls;

January 18--Park Inn International, Alexandria

January 25--Holiday Inn, Duluth

Anyone interested is invited, including professional and paraprofessional staff, case managers and family members. Cost: $15 for professionals; $5 for parents and persons with developmental disabilities (covers lunch, breaks, and registration materials).

In February and March, more intensive two-day workshops will be available in the same regions for persons interested in being trained to conduct Personal Futures Planning groups.

For registration and other information, contact: Pat Lyon, Human Services Research and Development Center, 357 Oneida, St. Paul, MN 55102. Tel. (612) 227-9117.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

LENDING LIBRARY SELECTIONS

Aging . . . A Shared Experience, (Videotape, VCR, 1/2 inch, 20 minutes), and Discussion Guide. This videotape was produced and directed by Matthew P. Janicki, and was funded by the Joseph P. Kennedy, Jr. Foundation. The production focuses on community integration of older Americans with mental retardation or other developmental disabilities. It tells the story of several such older Americans as they use senior services. Interviews with national figures include Dr. T. Fanklin Williams, Director of the National Institute on Aging, Congressman Claude Pepper, and Eunice Kennedy Shriver. This videotape is designed to be used for community education, staff training, and program development by workers in a variety of human service settings. Accompanying the tape is a Discussion Guide, which lists other resources for learning more about people with disabilities who are aging.

The following tapes were produced by the Governor's Planning Council on Developmental Disabilities:

An Interview with Lou Brown, 47 minutes, (April 1987). Lou Brown, Professor at the University of Wisconsin in Madison, talks about his research in the area of supported employment for persons with severe disabilities.

An Interview with Gunnar and Rosemary Dybwad, 47 minutes, (February 1987). The Dybwads speak from historical and international perspectives about the advancements made by persons with disabilities and the many challenges remaining in order to participate more fully in society.

An Interview with Pat Juhrs, (April 1987). Juhrs shares her experiences in creating a supported employment program for persons with autism in Rockville, Maryland.

An Interview with Betty Hubbard, (May 1987). Through Hubbard's experiences as a leader in the field of developmental disabilities, the viewer gains an appreciation of what went on behind the scenes in the development of landmark legislation and community services in Minnesota.

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